

**Partners in Care**

**Sandwell's Joint Carers' Strategy**

**2012–2015**

Final version  
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## **Introduction**

This strategy has been produced on behalf of the Carers Strategy Partnership Team. We would like to thank all the carers, professionals and organisations who have contributed in its production and in the consultation.

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## Summary

***“A carer is someone who spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has a mental health or substance misuse problems.”***

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. If statutory agencies had to replace the support that carers provide in Sandwell it would cost an estimated £664m a year, making them vital partners in health and social care. Section 1 sets out in more detail the strategic importance of support for carers. Carers have legal rights – to be consulted, to have their own needs assessed, to request flexible working and in some cases to have a short break or direct payment. However many do not seek or receive support.

Carers come from all walks of life and can be any age. They spend a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems – but they may not think of themselves as a ‘carer’. Young carers are children and young people who assume a level of responsibility normally associated with an adult, to support one or more people, often a parent.

One in seven of the workforce juggle the responsibilities of caring and paid employment, and one in five carers gives up work to care full time – the majority of these being experienced employees aged 45-64. Others forfeit education or other opportunities to meet the demands of caring. The ageing population and advances in medicine are increasing the demand for care and drawing more people into unpaid caring roles.

This strategy sets out the enormous contribution that Sandwell’s carers make to the lives of their friends and families; their needs and aspirations; and how we will work together to support them in the next three years. This document 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. This strategy provides a vision and framework for all agencies involved with carers of all ages in Sandwell, with a service model and local priorities for improvement. It explains what we plan to do to achieve these and make best use of resources in a climate of economic austerity. It sets out how we will work together as agencies and with carers themselves, to

achieve the shared vision, building on progress so far. It describes how we will support carers better through new partnerships between public sector services, third sector, communities, businesses and individuals. The strategy aims to frame our work for the next three years but will evolve in response to local and national demands.

It comes at a time of enormous change in public services, with a shrinking public sector, significant budget reductions and moves towards more collaborative and personalised approaches to family and community wellbeing. Carers are recognised as a vital part of the system of support throughout new policy guidance, in the coalition Government's policy guidance on supporting carers<sup>1</sup>, and in other policy on health, social care, employment, families and communities.

### **Wider impact**

The actions in this strategy support the local Strategic Shared Priorities "Active and Well People" and "Educated, Skilled People in Employment". We will do this by delivering services and approaches that:

- Reduce poverty
- Build skills and resources in the community
- Promote successful families and parents;
- Ensure children have a good start to life;
- Support successful young people
- Promote health and wellbeing
- Support independence and prevent crisis
- Help people to manage long term conditions
- Give more choice and control
- Support people with complex needs
- Safeguard children and vulnerable adults

### **Local needs**

Sandwell has high levels of ill health, health inequalities and deprivation so this suggests a great demand on carers as well as health and social care services. With changing social patterns there are more single parents, complex family structures and people living alone. Other local challenges include low levels of literacy and educational attainment. Demand for health and social care is high and rising, and the current economic climate means there are fewer resources available and there is additional strain on people's employment and personal resources.

In the 1991 census over 30,000 (more than one in ten) people in Sandwell said they were a carer. With an ageing population and increasing numbers of

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<sup>1</sup> *Recognised, valued and supported: Next steps for the Carers Strategy, 2010*.

severely disabled young people we expect this to have risen and go on rising. Half worked full time. Nearly half were over 50, and more recent local research identified over 2,000 young carers, several times the census figure. 17% were from Black and Ethnic Minorities, with a significantly higher percentage amongst young carers. In another local survey<sup>2</sup> 42% of carers said they didn't know what help was available.

An Equalities Impact Assessment (EIA) has been updated. Carers come from all walks of life, and as such, all the protected characteristics may apply depending upon individual circumstances. Key points include:

- **Age:** A high proportion of the local carer population is aged over 50, and the figures are set to rise in future years. In addition, many other carers also care for older people. We also have a significant number of young carers aged under 18 years;
- **Disability:** Research suggests that carers experience greater ill-health as a consequence of their caring role. A high proportion of carers also care for a disabled child and/or other disabled relative;
- **Race:** There are a significant number of BME carers in the borough and this is projected to increase in future years. Evidence suggests that the BME carer population faces additional disadvantages due to proportionately poorer health and deprivation, language barriers and cultural issues;
- **Sex:** There are slightly more female than male carers in the borough. There are also specific issues facing male carers which need to be addressed;
- **Sexual orientation:** Carers from the LGBT communities also face specific issues in accessing support;
- Carers often experience **multiple and additional disadvantage** in terms of poverty and access to employment and educational opportunities.

Most family, health and community care is provided by family, relatives and friends who do not always see themselves as carers or seek support. The skill, experience and dedication of carers in maintaining the health, well being and independence of vulnerable people is recognised in national policy but there is more to do to reflect this in the way that local services work with - and support - them. Carer support is valued at around £513 million each year in Sandwell – more than NHS services. However, there is evidence that carers experience worse health, more poverty and poorer educational and personal achievement than others. This has potentially lifelong effects on their own prospects and those of their families, particularly when they are children or

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<sup>2</sup> Carers, Employment and Services in Sandwell, S. Yeandle and others, University of Leeds, 2007

young people. When carers become unable to care there may be serious and costly consequences for agencies, families and communities. It therefore makes good financial sense to invest in support for carers, and to include them alongside the people they support, as expert partners.

We have brought together information from many sources about local carers of all ages, their services and what carers and other stakeholders say, to form a clear view of the issues, priorities and what needs to be done next. In particular we have referred to:

- Strategic Review of Carers' Services in Sandwell, 2009 – a stakeholder review with recommendations agreed by the joint Health and Wellbeing Board in March 2010.
- Independent Review of Carers' Services 2010 – an in depth look at cost and quality across adult / generic services funded by the Carers Grant
- Sandwell's Forgotten Children – research on Young Carers, 2008
- Young Carers Strategic Statement and Young Carers Plan, 2011.

**Our shared vision / outcomes are that by 2014** carers in Sandwell will...

- be actively planning and delivering carer support
- have easy access to information and advice
- be able to get support that is timely and flexible, and that fits their personal and family situation
- be enabled to maintain a balance between their caring responsibilities and a life outside caring
- feel safe, recognised, valued and supported as partners in care, at the heart of strong families and stable communities

**Our Shared Priorities** – we will achieve these things by:

1. Supporting carers to **identify** themselves early by improving **access** to information, advice and support
2. Recognising the value of what Carers do by **involving and empowering** them.
3. Enabling young and adult carers to fulfil their **education and employment** potential
4. Creating **personalised support** for carers and those they support, enabling positive family and community life and safeguarding people from caring responsibilities which are unsafe or harmful
5. Supporting carers to stay **mentally and physically well**

**Where are we now?**

We are proud to be building on **firm foundations**. Our achievements for carers in Sandwell to date include:

- A well established partnership of agencies and carers, working together to meet the needs of carers of all ages
- A very broad range of services to support carers with different needs – many of which offer direct access for carers.
- Two long-standing and award-winning voluntary carers' organisations: CARES and Sandwell Young Carers.
- Dedicated financial support for carers' services from the council and NHS organisations
- Award-winning services for emergency support, primary care NHS support, and for mental health and Asian family carers.
- Innovative and flexible services – 750 adult carers received direct payments to buy their own support in 2009-10, and over 180 parents of disabled children run their own support network and services
- A wide range of services for local carers, supported from various funding sources. These are set out in the Carers Joint Commissioning Plan.

We are also clear about **where we need to develop and improve**. Recent local reviews and research have told us that:

- We may not be reaching all carers who need support, particularly those who are children and young people, working, male, black and minority ethnic, older or supporting someone with dementia. Carers' services are in touch with a relatively small proportion of Sandwell's carers.
- Good, reliable up to date local information about carers is difficult to draw together without a register and regular survey of Sandwell's carers between census years.



- We need to use intelligence about carers in order to reach and support them better, especially those most at risk.
- There is a wide range of support available that is great for some but hard to 'navigate'.
- The system is not 'carer friendly' and 'family friendly' enough.
- Improving access to information about what help is available is key
- We could do better if we work together to support carers as members of families and communities, with more active engagement of important partners like education, employment services, GPs and hospitals.
- We should involve carers more and give them more choice and control.
- Some specific areas need development, including young carers, older carers and those looking after people with dementia.
- We could get better results for carers and better value for money if we strengthened and modernised our commissioning arrangements across agencies and service areas.
- We need to develop commissioning and governance arrangements with a more strategic and robust approach to investment and commissioning, focusing on delivering personalised, integrated, family-based support and developing a stable and effective market.

To achieve this, we will work jointly to **target investment** and take **action in the five priority areas** to deliver it. A separate **strategy delivery plan** will show in more detail what we will do to tackle each priority. Linked to this, there will **three commissioning plans**: the Carers Joint Commissioning Plan, The Young Carers Commissioning Plan and the Short Breaks commissioning plan (for families with disabled children).

Our Joint Commissioning Plan will set out how we will arrange services for adult carers in future, potentially with reduced health and social care funding. Having considered several options, we propose to **stop buying services delivering poorer value for money** and to change the commissioning framework to be fit for the future, planning for potential Local Authority budget reductions. From 2012 we propose to change our contracts for carer support, arranging services under **fewer, longer term contracts** under three types of service (though not necessarily three contracts):

- **Universal** – support for *all* carers, including information and advice, assessment, support planning, carers' register, emergency back-up and supported access to other community services. This also includes support and training for carers to get involved in improving services, to support each other and to develop and run their own services, with a support network.

- **Targeted** – for carers who are ‘at risk’ but not eligible for social care. Includes flexible short breaks and one-off, cash-limited grants to fund breaks and support of their choice.
- **Personalised** – personal budgets and packages of support for carers where they or the person they support are eligible.

We believe this approach will give better value for money and better results for carers, as it will bring services together and give them more flexibility to develop and improve. We also plan to change respite contracts to allow for the shift to personal budgets and direct payments.

**Young carers** have specific needs and require particular actions to be taken. The Young Carers Strategic Statement and Action Plan provide more details about these, in Appendix 6. This specific work will be led by Children, Young People and Families strategic commissioning.

We recognise that these changes present some new challenges, and we propose to adopt a **commissioning approach** that includes the following:

- Close engagement of carers in the design, selection and review of services
  - Collaborative work with existing and potential providers
  - Emphasis on sustainable carer-led approaches in services
  - Recognition of social return on investment
  - Minimal possible disruption for people using existing services
-

## Section 1: Definition, business case, vision and strategic priorities

### Why Support Carers?

***“A carer is someone who spends a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has a mental health or substance misuse problems.”***

Carers are valuable partners and the main resource available to the health and social care system locally. Their support is valued at £664m annually in Sandwell alone. Supporting carers prevents admission and speeds up discharge from hospital. It also prevents admission to care homes and reduces demand for home care support. Given the future constraints on public sector finances it is important that we support carers to maintain their own health and well being, as well as their caring and family relationships. Further work is needed to evidence the business case for supporting carers particularly with the emerging GP Consortia.

### The case for supporting carers includes:

- there are 31,500 carers in Sandwell (one in ten of the population)
- Carers contribute an estimated £664m worth of support in Sandwell
  - one in five of Sandwell's carers is caring for over 50 hours a week
  - 3% (about 1,000) in Sandwell care for three or more people
- National legislation and guidance recognises carers as equal partners in the provision of care for vulnerable people
- Carers are often disadvantaged by caring: poverty, ill health, education / training. As a high risk group themselves, carers are often multiply excluded and socially isolated:
  - 80% carers say their caring role has damaged their health
  - more than one in three carers 'doesn't want to wake up in the morning' due to poverty and depression
  - about half of carers in Sandwell are working - 10,000 are working full time
  - young carers are most likely to be caring for their mother
  - 16% carers say there is no-one they could rely on if they wanted to take a break
  - 42% said they had not taken a break since they started caring
- Carers have statutory rights - to an assessment and (parent carers) to a break, to be represented and consulted as part of community care processes and to manage direct payments for a disabled child.

- The carers programme (much of which is direct access) supports an estimated 20% (6,000) local carers each year, across all ages and client groups and including some specialist BME and minority groups
  - £1.4m is currently spent on supporting an estimated 6,000 carers each year – this amounts to £233 per carer.
- Formal social care support for carers (for example, provision of respite) is just the tip of the iceberg - nationally, only 6% carers said they had been offered a carers assessment (a statutory duty).
  - 37% carers are the ONLY support for their main cared-for person
  - 3% (about 1,000) carers in Sandwell care for three or more people
  - Stigma, social disadvantage and isolation mean that many carers are not in touch with services – especially young carers, BME carers, older carers, and carers of people with mental health /drug and alcohol problems.
- Carers often provide essential alternative support for many 'potential' users of social care services, and support that enables carers to continue to support someone safely at home can reduce the need for costly services. This makes carer support a vital element of any prevention strategy, as well as a key aspect of mainstream social care.
  - Research suggest that 38% admissions to nursing and care are due to carer stress (2001)
  - A national report (2011) suggests that a whole systems approach involving investment in care at home and carer support could save Sandwell £6m by reducing residential care costs

**Our shared vision is that by 2014** carers in Sandwell will...

- be actively planning and delivering carer support
- have easy access to information and advice
- be able to get support that is timely and flexible, and that fits their personal and family situation
- be enabled to maintain a balance between their caring responsibilities and a life outside caring
- feel safe, recognised, valued and supported as partners in care, at the heart of strong families and stable communities

To achieve this vision we will focus on five priority areas:

**1. Supporting carers to identify themselves early by improving access to information, advice and support**

|   | <b>We will..</b>   |
|---|--|
| 1 | improve the quality, consistency and range of <b>information</b> and how we <b>communicate</b> with carers to make it easier to get clear information and advice about carers’ rights, breaks and services, and to reach more carers in Sandwell – particularly those at greatest risk |
| 2 | develop a <b>central “hub”</b> , or “one stop shop” for carers in Sandwell   |
| 3 | develop a new Sandwell <b>carers list or register</b>  |
| 4 | <b>train staff</b> and share best practice so that carers are recognised and supported by all agencies   |

**2. Recognising the value of what Carers do by involving and empowering them.**

|   | <b>We will..</b>  |
|---|---|
| 1 | encourage carers to get involved, and to support themselves and each other, through <b>training and support</b>                   |
| 2 | support and develop a network of <b>self-help and carer-led</b> initiatives   |
| 3 | establish effective ways for carers to <b>participate actively</b> in planning, developing, commissioning and evaluating services |
| 4 | <b>measure</b> carer satisfaction, compliments and complaints more systematically and <b>use</b> the findings                     |

**3. Enabling young and adult carers to fulfil their education and employment potential**

|   | <b>We will..</b>   |
|---|--|
| 1 | work with relevant agencies to provide <ul style="list-style-type: none"> <li>○ support with <b>access to leisure, lifelong learning, volunteering, skills and work</b> opportunities</li> <li>○ support for carers to <b>develop and run their own activities</b> and services</li> <li>○ <b>equal access</b> for young carers to learning support and wider school life and opportunities</li> </ul> |
| 2 | work with employers to promote <b>carer-friendly employment</b> practices in the borough   |
| 3 | Improve support for <b>working carers</b>  |

**4. Creating personalised support for carers and those they support, enabling positive family and community life and safeguarding people from caring responsibilities which are unsafe or harmful**

|   | <b>We will..</b>  |
|---|---|
| 1 | develop <b>coordinated whole family support</b> , through <b>shared protocols</b> and <b>better practice</b> in referral, assessment and personalised support planning that recognises and supports carers in <ul style="list-style-type: none"> <li>• schools and colleges</li> <li>• community life</li> <li>• social care</li> <li>• health care</li> <li>• workplaces</li> <li>• transitions from childhood to adulthood</li> </ul> |
| 2 | give carers <b>more choice</b> in short breaks, through <b>direct payments</b> or <b>personal budgets</b>   |
| 3 | deliver <b>more flexible support</b> that sustains care and prevents crisis <ul style="list-style-type: none"> <li>• good support planning</li> <li>• emergency plans part of routine practice</li> <li>• emergency support</li> </ul>  |
| 4 | <b>target resources</b> at priority groups of carers: <ul style="list-style-type: none"> <li>• young carers</li> <li>• older carers</li> <li>• male carers</li> <li>• working carers</li> <li>• carers of people with dementia</li> </ul>   |

**5. Supporting carers to stay mentally and physically well**

|   | <b>We will..</b>  |
|---|---|
| 1 | Work with the new Clinical Commissioning Group(s) and NHS Trusts to agree and implement a plan to <b>improve NHS support</b> for carers. This may include the following actions: <ul style="list-style-type: none"> <li>• <i>Raise awareness of carers' issues amongst healthcare staff</i></li> <li>• <i>Provide access to local carers' information in key healthcare facilities</i></li> <li>• <i>Work with GP practices and patient groups to promote early intervention and carer support for those most at risk of ill health (possibly including health checks and breaks)</i></li> <li>• <i>Build carer and family consultation and support into care pathways at key points e.g. diagnosis, care planning, admission, discharge from hospital, end of life care, bereavement.</i></li> </ul> |

- |   |
|---|
| <ul style="list-style-type: none"><li>• <i>Make sure that protocols are in place to share information with carers</i></li><li>• <i>Include carers in relevant training opportunities, as extended members of the healthcare workforce</i></li></ul> |
|---|

## **Strategic actions**

### 2012-13

- Develop engagement of carers, building on existing involvement to create a carers forum and involvement in commissioning
- Ensure effective partnership, establishing agreements with emerging NHS commissioners
- Design new service specifications and monitoring arrangements
- Develop the local market by supporting existing and potential providers in preparation for new contracts
- Procure services
- Ensure smooth transitions for carers in any handovers to new providers

### 2013-14

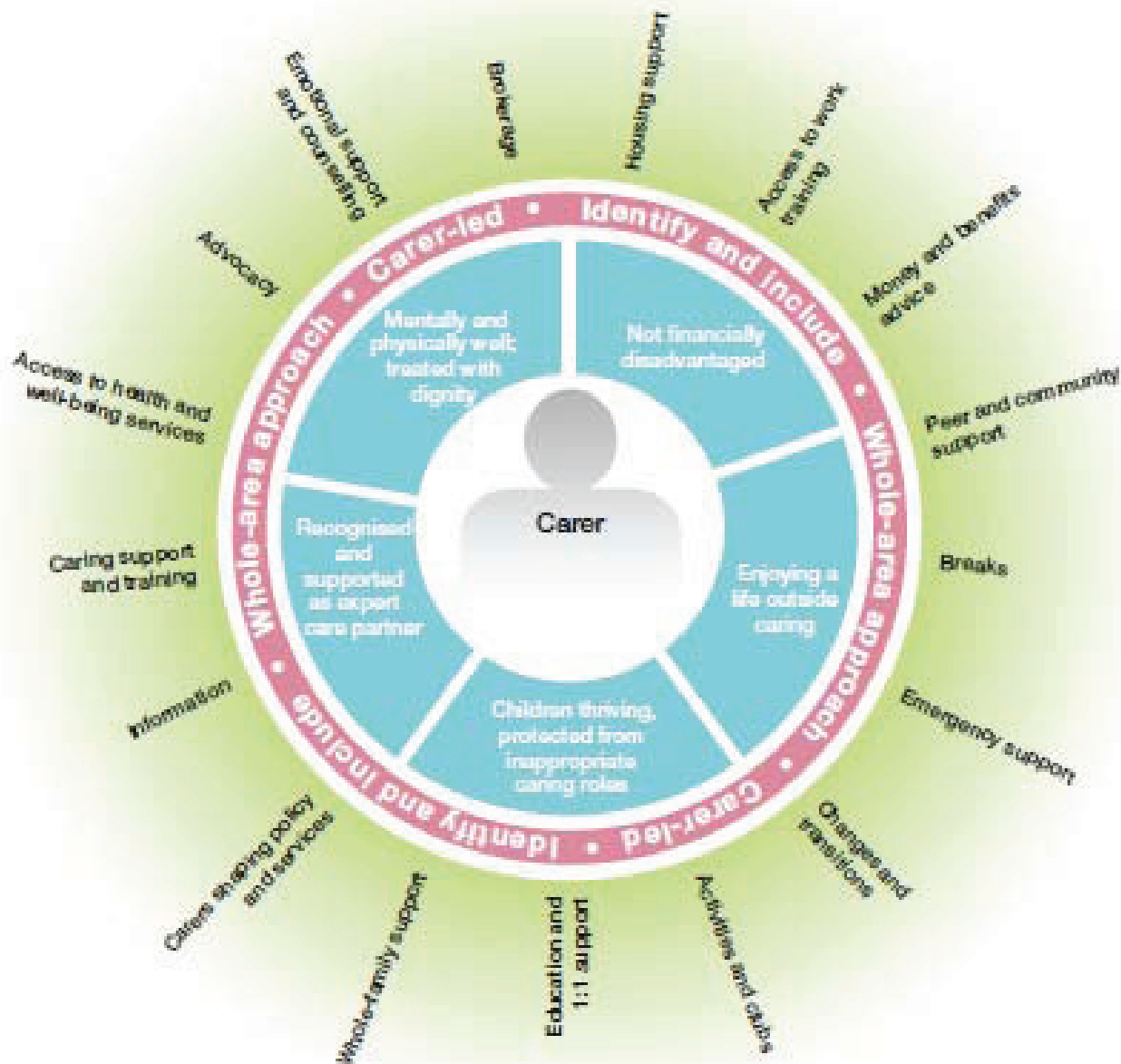
- Maintain and develop engagement of carers in commissioning
- Ensure effective partnership and joint commissioning
- Manage introduction of new contracted services
- Monitor quality, performance and outcomes
- Review and improve service delivery

### 2014-15

- Maintain and develop engagement of carers in commissioning
- Ensure effective partnership and joint commissioning
- Monitor quality, performance and outcomes
- Review contracts
- Review and improve service delivery
- Review strategy

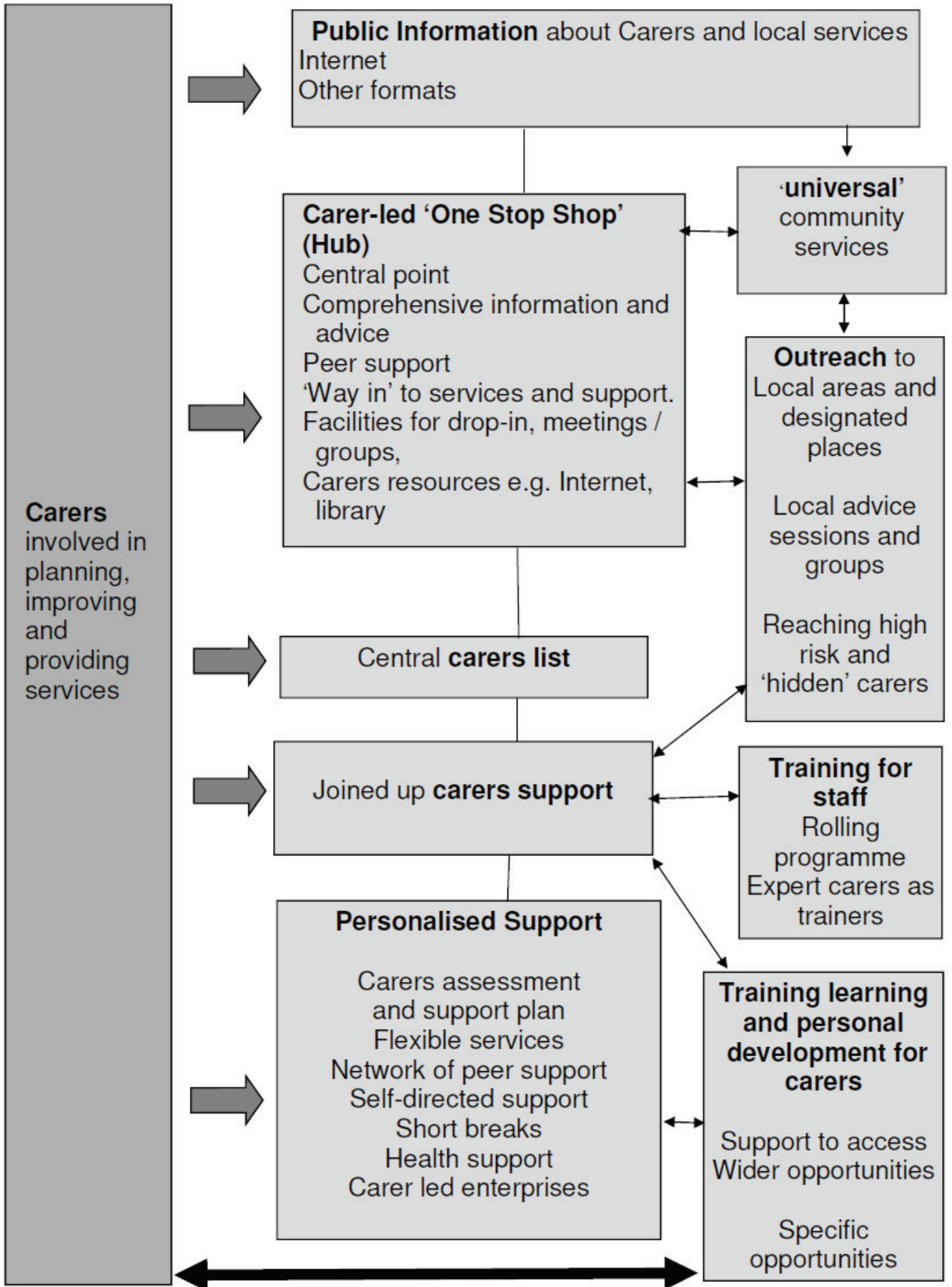
## Our new Service Model

We have based our local approach on a national model of comprehensive Carer Support. This shows the complete range of support that should be available (outer band); three underpinning approaches (pink middle band); and the five outcomes for carers from the national carers' strategy (blue inner band), all based around carers' individual and local needs (centre).





**Sandwell's Service Model for carer support: 2014**



## Commissioning approach.

Organisational changes within the Council and PCT will present opportunities and challenges and current structures for commissioning are likely to evolve as a result. The creation of the new People Theme in the Council offers the opportunity to deliver a family-based approach. Traditionally, strategic commissioning has been done by Councils and PCT's. However, organisational changes will mean the NHS commissioning responsibility being transferred from PCT's to new Clinical Commissioning Groups.

The way we will jointly commission support for carers will be based on the following principles:

- Pooling or aligning resources to deliver joined up services across agencies wherever possible.
- Commissioning services that will deliver the new service model, priorities and outcomes in this document and in line with legislation and guidance that may change over time.
- Close engagement of carers in the design, selection and review of services
- Collaborative work with existing and potential providers
- Emphasis on sustainable carer-led approaches in services
- Recognition of social return on investment and added value.
- Minimal possible disruption for people using existing services
- Planning, arranging and buying services more “smartly” and innovatively across agencies and service areas to get the best results for carers and best value for money
- Encouraging innovation and a vibrant market of service providers, especially amongst the voluntary and community sector, recognising their importance as local partners
- Promoting equality and diversity in all services
- Safeguarding vulnerable adults and children

We shall do this in line with the strategic approach to a personalised health and social care offer, reaching out to those carers most in need whilst providing a core offer for all carers to prevent crisis and sustain caring relationships. The following diagram shows how we will structure the commissioning of carer support within the three broad levels of support:

- **Universal** – support for *all* carers, including information and advice, assessment, support planning, carers' register, emergency back-up and supported access to other community services. This also includes support and training for carers to get involved in improving services, to

support each other and to develop and run their own services, with a support network.

- **Targeted** – for carers who are ‘at risk’ but not eligible for social care. Includes flexible short breaks and one-off, cash-limited grants to fund breaks and support of their choice.
- **Personalised** – for carers of people with more complex needs. Includes support for carers via personal budgets where the person they support is eligible for social care; and integrated, tailored support between health and social care agencies.

## Section 2: Making it Happen

### 2.1 How we will put this into action, lead, monitor and measure progress.

The Council’s Director of Strategic Commissioning is responsible for creating and delivering this partnership strategy for carers, through the **Carers Strategy Partnership**. This body reports to the Health and Wellbeing Board of the Sandwell Partnership, which is responsible for strategic development of health and well being of local people, across the Local Authority, Primary Care Trusts, NHS Trusts, and Voluntary & Community Sectors.

The **Carers Strategy Partnership** is made up of representatives from agencies who arrange and provide services, and carers themselves (see appendix 4). The partners are fully committed to delivering the strategy by taking the actions set out in section 3. We plan to give carers a stronger voice in this partnership. A Carers Provider Forum is also held regularly to improve communication and co-ordination with a wide range of providers (see appendix 5). We intend to hold two Carers’ Forums with carers each year, plus some special forums for Young Carers, in partnership with the Children, Young People and Families lead.

This strategy is funded through specific government grants and mainstream investment by partner organisations across all service areas. This strategy is an evolving document and may change over time in response to local and national developments.

We plan to deliver this strategy through **three plans**: the strategy delivery plan (overview of all key developments), the joint commissioning plan (specific plans for buying services) and the specific Young Carers Action Plan

(appendix 6). The Council's Strategic Commissioning directorate will develop specific commissioning plans for young carers and parent carers in their Young Carers commissioning plan and a Short Breaks commissioning plan.

Progress will be monitored every three months and reviewed annually by the Carers Strategy Partnership team. A joint team of commissioners will work together to develop a more coordinated approach to carers' services. Both of these will involve carers directly, and we plan to engage carers in projects. A communications and engagement plan) sets out how we will communicate and engage with carers.

Our delivery plan for this updated strategy is based on the carers' outcomes in the national model of comprehensive support, and the concept of good governance. Our delivery and commissioning plans will have specific milestones and measures built in so that we can measure progress and performance. A "balanced scorecard" (appendix 3) of a set of measures will be used to monitor how we are doing overall. We particularly want to include a measure what local carers think about services, and to increase their influence in service development.

## 2.2 Our Values and Principles of Practice

*We will **recognise** carers*

- in their caring role
- as individuals in their own right, and in the case of young carers, as children first
- as members of families and communities
- as partners in health and social care
- as needing support to sustain the caring role and when it ends

*We will respect carers' **Rights** to:*

- a voice in service planning, provision and evaluation
- reliable, relevant, accessible and comprehensive information
- an assessment of their own needs
- the same access to learning, leisure and work as their peers
- private and family life
- good quality, affordable services
- support and practical help for the management of caring
- protection from harm through inappropriate caring responsibilities

*We will give carers **choice and control** in services*

Carers should have the same chances to do the things that others take for granted. We will make sure carers and the people they support feel confident

in seeking and choosing the support they need. We will support carers to determine whether or not they wish to continue to provide care, and to get the right balance between providing care if they want to, and maintaining a life outside of caring. This means being able to work when they can, to have a decent income, to maintain other responsibilities and social networks and to have opportunities for leisure and learning. We will empower them to look after their own health and well-being. We will also recognise and support the important role of carers in making choice and control a reality for the people they care for. Carers will be treated as expert partners in the delivery of health, well-being and independence.

*We will aim to **prevent crisis***

We will provide practical, emotional and flexible support that builds family resilience and helps to sustain carers in their caring role. Effectively supporting carers helps reduce costly interventions such as hospital, residential care or looked-after children. Carers, because of the very nature of their caring responsibilities, are often at increased risk of isolation and social exclusion and low level interventions can be essential in reducing this risk. We will also help carers to plan for the future and for emergencies, including helping the person they support to move on to other living arrangements, as and when necessary.

*We will focus on **outcomes***

When planning, commissioning and evaluating services we will consider the actual difference they make to carers' lives, working with carers as expert partners to decide what services represent the best investments. We will do this by giving carers a personal budget wherever possible, using the best evidence of what works, and learning from leaders in the field and asking people who have used services.

*We will work in **partnership***

We aim to give carers far more control of services at an individual and family level, and communally. This means negotiating new relationships and responsibilities between individuals and agencies. We will work closely with carers themselves to agree effective ways of doing this. All partner agencies will work together to deliver this strategy and improve outcomes for carers.

*We will recognise the **diversity** of carers*

Ensuring equal access to support means recognising that different carers may need different approaches. We will continue to listen to – and work with – carers in different areas and in different groups to make sure they have fair access to services.

*We will **safeguard** carers and the people they care for:*

The experience of abuse and neglect is likely to have a significant impact on a person's health and well being. By its very nature abuse – the misuse of power by one person over another – has a large impact on a person's independence. Neglect can prevent a person who is dependent on others for their basic needs from exercising choice and control over the fundamental aspects of their life, and cause humiliation and loss of dignity. All people have a right to live their lives free from violence and abuse. This right is underpinned by the duty on public agencies under the Human Rights Act (1998) to intervene proportionately to protect the rights of citizens. It follows that all citizens should have access to relevant services for addressing issues of abuse and neglect. All agencies will commission and provide services in a way that safeguards carers and the people they care for.

### **Section 3: Appendices**

- 1. What we know about carers in Sandwell**
- 2. Carers Policy and legislation**
- 3. Performance and outcome measures for carers**
- 4. Terms of reference: Sandwell Carers Partnership and commissioning team**
- 5. Local references and useful contacts**
- 6. Young Carers strategic statement**
- 7. Case studies: why carer support makes good financial sense**
- 8. How we consulted partners about this strategy**

## APPENDIX 1: what we know about carers in Sandwell

### Sandwell overview



- Sandwell is Sandwell is a Metropolitan Borough formed in 1974, and is one of seven authorities that makes up the West Midlands conurbation.
- **Population:** 291,000 (Jun'09).
- **Ethnicity:** 23% of the population are from black and minority ethnic groups (Jun'07).
- **Health:** Life expectancy is 74.9 years for men and 80.7 for women (Marmot Review, 2011).
- **Unemployment:** 7.0% of the working age

population claim Job Seekers Allowance (Jan'11).

- **Housing:** Approximately 126,000 dwellings (Mar'09).
- **Environment:** Area of 8,600ha, of which 15.2% is parks or open space (2005).

### Local Challenges

- Sandwell is the 12th most deprived local authority in England and is the 4<sup>th</sup> hardest hit local authority in terms of unemployment across England
- Sandwell has the 6<sup>th</sup> lowest life expectancy of any local authority in England for men and 27<sup>th</sup> lowest for females (Marmot Review, 2011).
- The most common group in Sandwell are those who are 'upwardly mobile families living in homes bought from social landlord's (27.3%) and those in 'close knit, inner city and manufacturing communities' (24.0%). Both of these groups are found in far higher percentages than the rest of England.
- An estimated 20,500 children in Sandwell live in poverty.
- Homelessness is rising
- Population will grow slowly over the next 20 years by 5.5% to 309,000
- Sandwell is ageing but not as fast as England, over 65s will increase by 13% by 2025 compared to 30% nationally. We need to ensure that plans are fit for the future.
- 55% of Sandwell's older population have long-term illness, compared to 47% in the whole of England (POPPI). As Sandwell's population is ageing, this will affect Sandwell's carers in the future.
- We have a growing ethnic population. By 2029 people from Black and Minority Ethnic populations will make up 30% of the population with

Bangladeshi and Pakistani populations doubling in size due to a higher birth rate. A significant number of mainly working age people have been moving into Sandwell from Eastern Europe, notably Poland. These populations have different health needs that are not fully understood.

- Educational attainment is lower than average but improving, with more students in higher education and better results in schools. However, there are high levels of young people not in education, employment of training, and school exclusions. Fewer people than average in Sandwell are progressing to levels of education higher than NVQ1.
- Sandwell has the 14<sup>th</sup> lowest life expectancy of any local authority in England for men and 25<sup>th</sup> lowest for females. Across Sandwell there is a wide variation in life expectancy.
- The health of Sandwell is improving, but not as fast as the England average. There are high levels of alcohol related illness, teenage pregnancy, obesity, heart disease and cancer.
- Large proportions of the elderly and working age populations have long-term illness.
- The number of people with learning disabilities from black and minority ethnic communities is increasing
- More people with learning disabilities are living into older age, some of whom are living also with dementia
- More severely and multiple disabled children are surviving into adulthood

Sources: Joint Strategic Needs Assessment 2010, State of Sandwell report 2008, local service reports)

## Who are carers?

*'I care for mum more than myself. There isn't the correct support out there for us. I provide personal and emotional support and I don't go to school'*

Comment from a young carer: local consultation.

*'I want to be listened to, respected and valued as a carer'*

Comment from a carer: local survey

Carers spend a significant proportion of their time providing unpaid support to a family member, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems. Carers....

- come from all walks of life
- can be any age, and may be working, in education, retired, or full time parents



- are not paid for what they do, although they may be entitled to certain state benefits
- often give up paid work, education or other opportunities as caring can be a full-time commitment
- often do not want to be 'defined' by their caring role and may not associate themselves with the term 'carer'

Changes in the age structure of the population and advances in medicine are increasing the demand for care and drawing more people into unpaid caring roles.

## **How many people are carers?**

### ***Nationally:***

The 2001 Census collected information about carers. This indicated that there are approximately 6 million carers throughout the UK, around 10% of the total population, or 12% of the adult population and 15% of all households.

The national Survey of Carers in Households 2009/10 obtained more detailed information about adult carers:

- Carers were more likely to be women than men; 60 per cent of carers in England were women.
- Carers were most likely to be aged 45-64 (42%); a quarter (25%) were aged 65 or over.
- Around half (46%) of carers were in paid employment, 27 per cent were retired from paid work and 13 per cent were looking after their home or family

### ***In Sandwell:***

- The 2001 Census recorded 30,130 carers of all ages in Sandwell, of which 14903 were male and 17439 were female. This is more than one in ten Sandwell residents, slightly more than the national proportion.
- Of these, 610 were young carers (under 16). Local research<sup>3</sup> has since identified 2,172 young carers in the borough, including 1,339 of primary school age and 833 of secondary school age.

All commentators expect demand for care to increase in coming years.

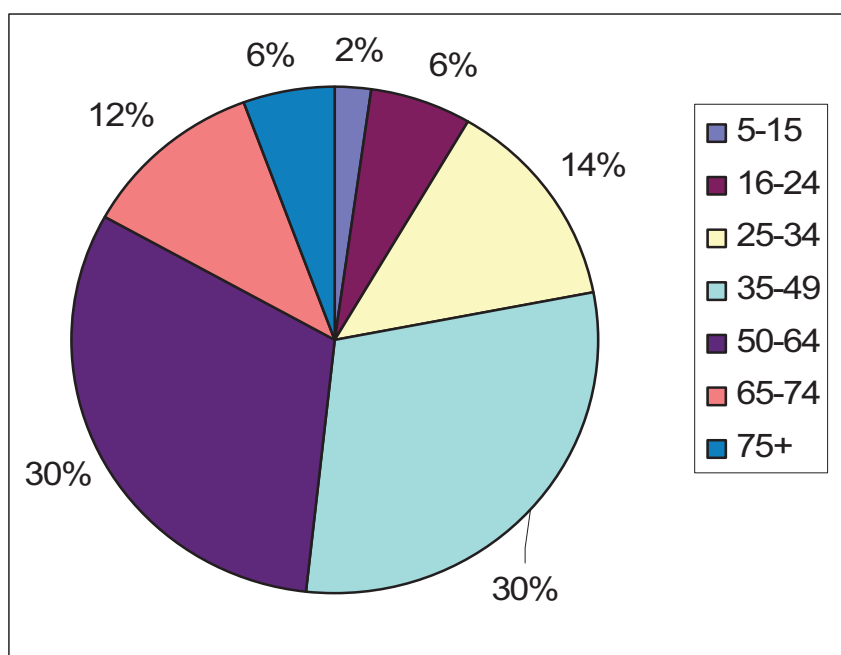
## **A profile of Sandwell's carers**

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<sup>3</sup> "Sandwell's Forgotten Children" needs analysis, 2008

A local statistical profile of caring, based on the 2001 Census, is provided in Appendix 1. This data is now nearly ten years old, and with population changes must be treated with caution. We might anticipate for example predicted rise in the numbers of older (and very old) people, and black and minority ethnic groups, there will be more people needing and providing care, and more carers amongst BME communities. We will keep this strategy under review as new data becomes available.

### Age



**Figure 1: Carers in Sandwell by Age**

Source: 2001 Census Standard Tables, Crown Copyright 2003. Note: Data in this figure are for carers of all ages.

The majority of carers are of **working age**, with three fifths of carers in the borough aged 35-64 (for many people years in which their career or earnings are very important). Looked at differently, **nearly half of all carers are over 50**, with 18% aged over 65 and 6% over 75. The older population is forecast to rise significantly in future years, for example there will be an extra 2,800 people aged over 75 in the borough by 2020. With an estimated one in five people over 80 having some form of dementia, this forecast has significant implications for carers.

The 2001 census identified 30,086 carers living in Sandwell including 610 children with caring responsibilities (2% aged under 16 years). In 2008 a local needs analysis carried out by Sparrow Hawk consultancy (“Sandwell’s Forgotten Children”) identified 2,172 young carers (1,339 primary school age and 833 secondary school age). This suggests that many young carers are “hidden” from the system.

Nationally 56% of young carers live in lone parent families, and one in ten cares for more than one person. 13% of primary school age, and 27% of secondary school age experience some problems at school.

The borough's population of people aged 85+ is set to increase by 1,900 people (up 38%) by 2021. In this age group 78% of people already report having a LLTI, and 42% are in poor health. These figures have risen since 1991, when 57% of the 85+ group had a LLTI. With age, many older people become frail (4,855 people in Sandwell were aged 85 or older)

### **Gender**

There are slightly more female than male carers in the borough. Men are more likely to be working, and working full time in addition to their caring role.

### **Deprivation**

Caring is particularly concentrated in areas of socio-economic deprivation. 23% of carers in Sandwell live in **workless households** (13% of carers providing 1-19 hours of care a week, 32% of carers providing 20-49 hours and 43% of carers providing 50+ hours) compared with 18% of people who are not carers. Carers often experience **multiple and additional disadvantage** in terms of poverty and access to employment and educational opportunities.

### **Ethnicity**

17% of carers (over 5,200 carers) belong to ethnic minority groups (Figure 2), a little below their share of the borough's total population (22%). This is not surprising, given the younger age profile of ethnic minority groups and possibly some cultural differences in relation to perceptions of caring. Among those of working age, Bangladeshi men have higher rates of caring than White British men and women. A report by Leeds University showed that these higher rates of caring are related to higher rates of sickness and disability in ethnic minority households. Significantly more *young* carers in Sandwell belong to black minority ethnic (BME) groups than the national average (15%), in both secondary (40%) and primary (33%), groups.

We have a growing ethnic population, by 2029 people from Black and Minority Ethnic populations will make up 30% of the population with Bangladeshi and Pakistani populations doubling in size due to a higher birth rate. A significant number of mainly working age people have been moving into Sandwell from Eastern Europe, notably Poland. These populations have different health needs that are not fully understood.

### **Health**

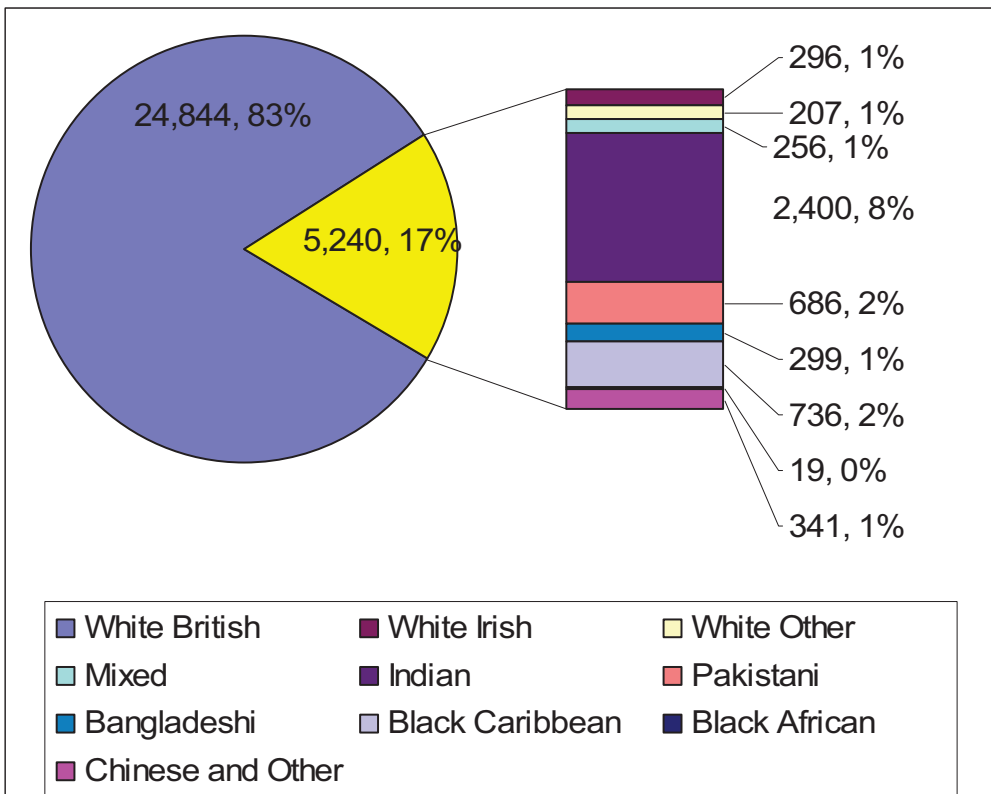
In the 2001 census, over 47,000 households (41%) in Sandwell contained at least one person with a limiting long-term illness (LLTI). This included 880

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parents who identified themselves as carers in households which contained a sick or disabled child. 59,611 people in Sandwell had a LLTI, among them 28,128 who are also in poor health.

Research suggests that carers experience greater ill-health as a consequence of their caring role. A high proportion of carers also care for a disabled child and/or other disabled relative;

**Ethnicity**



**Figure 2: Carers in Sandwell by Ethnicity** Source: 2001 Census Standard Tables, Crown Copyright 2003. Note: Data in this figure are for carers of all ages.

There is a significant number of BME carers in the borough and this is projected to increase in future years, as the older BME population is projected to rise dramatically. Evidence suggests that BME carers face additional disadvantages due to higher rates of deprivation and poor health, as well as language barriers and cultural issues.

**Sexual orientation**

There are no statistics on the number of Lesbian, Gay, Bisexual and Transgender (LGBT) carers in Sandwell, and we know little about their specific needs. Although some carers from LGBT communities are currently using local services they may face specific issues in accessing support.

## What do carers do?

*'My brother is a handful and it's hard for my Mum and sometimes I have to support Mum and him. I help my brother with his homework and then I have to do household tasks'*

Comment from a young carer: local consultation

The national Survey of Carers in Households 2009/10 found that:

- Around two in five carers (37%) were the **only support** for their main cared for person, while the remainder reported shared caring responsibilities.
- 83 per cent of carers were looking after one person only, 14 per cent were looking after two people and **3 per cent looked after three or more people**. In Sandwell this last group would equate to around 900 carers.
- Carers performed a wide variety of tasks for the person they mainly cared for - they were most likely to provide
  - practical help (such as preparing meals, shopping and doing the laundry) (82%),
  - keep an eye on the person they cared for (76%),
  - keep them company (68%) or
  - take them out (62%)
  - help with paperwork (49%)
  - help with care services and benefits (47%)
  - personal care (38%)
  - physical help (38%)
  - giving medicines (35%)
- Carers who provided care for **20 or more hours per week** were more likely than those providing care for fewer hours to
  - perform every single task
  - help with personal care (57% compared to 21%)
  - provided physical help (54% compared to 23%)
  - help to give medicines (54% compared to 17%)
- Carers who were looking after someone in the **same household** were much more likely than those who were caring for someone living elsewhere to
  - do longer hours of caring
  - do more tasks
  - perform the more personal tasks such as personal care (54% compared with 22%), physical help (49% compared with 25%) and giving medicines (50% compared with 18%).

An earlier General Household Survey revealed that two thirds of carers had daily responsibilities and more than half of all respondents provided care day and night.

- Responsibilities may change over time and may be difficult to predict day to day
- Becoming a carer may be a gradual process or the result of a sudden event

### **Time spent caring.**

The national Survey of Carers in Households 2009/10 found that

- 7 per cent of carers had been looking after their (main) cared for person for at least ten years, including 8 per cent who had been providing support for 20 years or more.
- A third (32%) of those who provided care for more than 20 hours per week had been a carer for more than ten years, compared with 22 per cent of those who cared for less than 20 hours per week.
- Those who were caring for someone in the same household were far more likely than those who provided care elsewhere to have supported their (main) cared for person for more than 10 years (35% compared with 18%).
- Six in ten carers (61%) anticipated that the amount of time they spend caring will increase in the next five years, while just 8 per cent felt it would decrease.

Sandwell Census data suggests that more than four out of ten (less than the national average of 48%) carers spends over 20 hours a week caring, and **one in five carers (7,805 people) is caring for over 50 hours a week.**

Local research suggests that compared to the national average of 10%, **more young carers in Sandwell spend over 20 hours per week caring (18%),** and provide more support than nationally for 'intimate care', 'childcare' and 'other'care.

We estimate that the support provided by unpaid carers in Sandwell would cost £513 million to deliver each year if it had to be replaced. Most carers give their help willingly, and want to work together with service providers; often they help those they care for to remain at home where they wish to be.

Demand for care is expected to increase in coming years as the number of older and disabled people in the borough rises.

### **Who do carers support?**

*'When my sister became 19 Mum couldn't afford to pay for respite so I have to care more'*

Comment from a young carer: local consultation

The national Survey of Carers in Households 2009/10 found that

- 61 per cent of carers were looking after women,
- 39 per cent were looking after men
- Half (50%) were looking after someone aged 75 or older
- 8 per cent were caring for someone under 16.
- Carers were most likely to be looking after a close family member, such as a parent (33%), a spouse or partner (26%) or a child (13%).
- 9 per cent said their main cared for person was a friend or neighbour.
- The most common reasons why care was required included a physical disability (58%), a long-standing illness (37%) or a sight or hearing loss (20%). In addition, 17 per cent mentioned that their main cared for person had problems connected to ageing.
- 22 per cent said their main cared for person was affected both physically and mentally.
- Around two thirds (66%) of carers said their main cared for person had some kind of regular contact with a health or social care professional
- 63% per cent of carers said their main cared for person did not go to any outside places or activities. Around one in five carers (19%) said the person they looked after went to a social club, support group or other club, 10 per cent said they went to school or college, 8 per cent mentioned a day centre and 5 per cent said their main cared for person went to work.
- Only 13 per cent of carers said that their main cared for person regularly made use of a community or voluntary transport scheme.

Local research on young carers indicated that **mothers were the individual most likely to be receiving care from young carers in Sandwell**, both for 5-10 year olds (47%) and 11-17 year olds (52%). **Nearly half of Sandwell's young carers care for an individual with physical disabilities**, whilst 20% support someone with a learning disability and 4% look after someone with sensory impairment. However it appears that fewer young carers look after someone with a mental illness in Sandwell (18%) than nationally (29%). Alcohol Concern estimate that there are up to 1.3 million children in the UK affected by a parental alcohol problem.

Compared to the national average of 4%, young carers in Sandwell are far more likely to care for their grandparents, with **44% of young carers aged 5-10 and 21% of those aged 11-17 caring for their elders.**



## The Impact of Caring

*'The needs of carers and the person they look after should be properly considered'*

Comment from a carer: local survey

### Health

*"I get upset if it is hinted I cannot cope with the housework and look after S properly but I am desperate to have just a little time to myself. The only time S goes out is to the Doctors or hospital - this is not good for him or me"*

Comment from 2011 consultation

Caring can be detrimental to your health. An analysis by Carers UK's of the 2001 Census findings, *In Poor Health*, found those caring for 50 hours a week or more are twice as likely to be in "not good" health as those not caring (21% against 11%). This difference is especially marked amongst younger people. In the 18 to 25 age group those providing 50 hours care or more per week are three times more likely to be in "not good health" as people of that age group not providing care (8% against 2.5%). This backs up earlier research, including a 2002 study, which found that carers were over twice as likely to have mental health problems if they provided substantial care; 27% of those providing over 20 hours per week had mental health problems compared to 13% of those providing less than 20 hours of care.

The national Survey of Carers in Households 2009/10 found that

- Just under two thirds (66%) of carers who spent 20 hours or more caring per week reported adverse effects upon their health as a result of this provision, compared to 39 per cent of those who were caring for fewer hours who felt this was the case.
- All negative effects of caring upon health were more prevalent in those providing care for 20 or more hours per week than those providing fewer hours of caring, and these providers of more intensive care were at least twice as likely to report feeling tired (47% compared with 21%), disturbed sleep (35% compared with 16%) and feeling depressed (25% compared with 12%).
- Carers who were looking after someone in the same household were far more likely than those supporting a person living elsewhere to report adverse effects upon their health as a result of caring (62% compared with 42%).

Those providing care over a long period of time are at a particular risk of poor health and both mental and physical health are likely to deteriorate the longer the carer has been caring. Analysis of the British Household Panel Survey has demonstrated that the health of carers is more likely to decline over time than the health of non-carers and many of the detrimental changes can be

attributed to the caring role. Research by Michael Hirst for the University of York indicates that the physical health of carers is more likely to decline after the first year of caring. The research also identifies spouse carers and mothers looking after a disabled child as being most at risk of psychological distress and the period immediately after caring ends as a period where ill health is likely to increase.

Other factors contributing to poor health amongst carers are low incomes and lack of breaks from caring. Research by Carers UK found seven out of ten carers worried about their finances and six out of ten believed this had a negative effect on their health. Other research has found that those not receiving a break were far more likely to experience mental health problems, 36% compared to 17% of those getting a break. Many carers often report ignoring their own health because of a lack of alternative care and the absence of emergency planning.

The combined effects of poverty and ill-health can lead to isolation and leave carers ill equipped to return to work as and when caring ends.

### **Financial**

The financial costs of caring can be significant. Research by Carers UK found that 77% of carers who responded to the survey were worse off financially as a result of becoming carers, mostly attributable to the extra costs of disability within the family. Four out of ten carers said that charges for community care services caused major financial problems. A third of carers in the survey qualified for Income Support, almost all respondents in the survey received Carer's Allowance and nearly six out of ten carers lived in households where nobody was earning.

The national Survey of Carers in Households 2009/10 found that only 11 per cent of all carers reported receiving Carer's Allowance and 27% received Disability Living Allowance/Attendance Allowance.

### **Work**

*'I would like more opportunities to learn and work alongside my caring role'*

Comment from a carer: local survey

The 2001 Census found that over 3million people combine work with caring responsibilities. This is roughly one in eight workers in the UK. Of these, over 2million work full time and 1million part time. Male carers are more likely to be in work than females. Six out of ten male carers work, and 90% of these work full time. Eight out of ten carers are of working age i.e. aged 16 to 65. Combining paid work with caring causes stress and can lead to carers giving up work. The national Survey of Carers in Households 2009/10 found that amongst carers of working age, 26 per cent felt their caring responsibilities

had affected their ability to take up or stay in employment, although nearly three quarters (74%) did not feel this was the case. Carers aged 35-54 were most likely to say that caring had affected them in this way (32%).

The national Survey of Carers in Households 2009/10 found that the groups of Carers who were most likely to say their employment prospects had been affected because of the care they provide were:

- Aged 35-44 (34%) or 45-54 (30%);
- Those looking after the home or family (46%) or those working part-time (35%);
- Caring for someone in the same household (38%);
- Providing care for 20 hours or more per week (40%);
- In bad or fair health (34% and 32% respectively);

76% of carers in Sandwell (22,971 people) are of working age; 43% are men and 57% women. **Around 10,000 of Sandwell's carers (a third of all carers) are working full time.** Among people of working age, the likelihood of being a carer rises with age (Figure 4). Among **male carers** in Sandwell, most also hold paid jobs. Even among those men who have very heavy caring roles (50+ hours per week) 36% are in full-time paid work. However these male carers also have high rates of sickness and disability (17%), and a significant minority care for their family full-time (24%).

Almost a half (48%) of **female carers** who care for 20-49 hours per week have paid jobs too. They are equally divided between those in full-time (24%) and those in part-time paid work (24%), while 7% are themselves sick or disabled and 32% care for their family full-time. Among women who care for 50+ hours per week, 10% are sick or disabled themselves.

Working carers are thus a very important group yet many feel poorly supported, suffer impacts on their health and financial position, and feel they need more help from formal services.

### ***Learning and life beyond caring***

*“With physical tiredness and waking up late, many young carers were late to school, though this was more a common factor in secondary schools than primary. Homework, more often than not, was not completed on time, however young carers seemed to show a certain sense of respect for the purpose of school work based on them ‘growing up’ and maturing more quickly than their peers.”*

Extract from Sandwell's Forgotten Children

There is clear evidence of the impact on the learning and life chances of young carers. Local research revealed that more of Sandwell's youngest carers miss school than the national average. The impact of being a young carer can also include bullying, not enough time for homework or school activities, underachievement, depression and self harm.

Adult carers also have difficulty accessing learning and work opportunities, social and leisure activities. Many give up work to care for someone and find it hard to get back into employment when caring comes to an end.

The national Survey of Carers in Households 2009/10 found that the groups most likely to feel that their personal relationships, social life and leisure had been affected because of the care they provided included women, people aged 45-54, people looking after home or family, those who were caring for someone in the same household, those who were caring for 20 hours or more per week and those who described their own general health as 'bad'.

## Services for carers

The national Survey of Carers in Households 2009/10 found that

- **Only a small number (6%) of carers said they had been offered a carer's assessment** and 4 per cent had actually been assessed. Two per cent said they had been offered a review of their own needs and 1 per cent said they had actually had such a review.
- **67 per cent of carers who had been assessed said they had received a service of some kind** as a result of the assessment. The most common services were equipment such as mobility aids (26%), services for the person they care for (22%), an assessment of the person they care for (21%) and information about benefits (20%).
- Almost two thirds (66%) of carers reported that they would need someone else to care for their main cared for person if they wanted to take a break for a couple of days. For shorter breaks from caring of a couple of hours, 27 per cent of carers said that someone else would be needed if they wanted to take a break.
- 84% of carers who said that someone else would be needed if they wanted to take a break for a couple of days did have someone (almost always a relative) they could rely on to look after the person they cared for. However, **16 per cent (or, 11% of all carers) said there was no one they could rely on if they wanted to take a break.**
- 58% of carers who would need someone else to look after the person they cared for said they had had a break of 2 days or more, meaning that **a large minority (42%) had not taken such a break since they started looking after their main cared for person.**

- 3% of all carers reported that their main cared for person had made use of a sitting or befriending service in the last year.

### **Local services**

The current picture of local carers' services is complex. Some are geared towards carers based on the needs of the person they support, e.g. Dementia, Learning Disability, HIV, Drug and Alcohol, Mental Health, Children with Disabilities etc. Others are generic – available to all carers, or specifically for certain kinds of carer, like young carers. This picture is changing, with the introduction of personalised, family-based approaches and more user- and carer- led support.

Support comes in many forms, including information and advice, emotional support, time off and short breaks, emergency support, learning opportunities and practical help. Of course, carers need support from many other places too, including their social networks, employers and the general services they and their families use.

Investment in these services locally comes from a number of sources including allocations to the Local Authority and Primary Care Trust. Third sector partners also access significant funding from external sources, and many carers buy support themselves. We currently invest an estimated £5million each year on specific support for carers in Sandwell.

A **local strategic review of carers services** in 2009 considered the facts and figures about local carers and the services in place, with over 249 people being involved.

The review concluded that:

- Support was great for some but hard to 'navigate'
- The system is not 'carer friendly' enough
- We could do better if we work together
- We should involve carers more
- We need a shared model
- Some specific areas need development
- Stronger leadership in all agencies is needed to make improvements happen

A model for future services was developed with stakeholders, and the review made fifteen recommendations that were agreed by the Health and Wellbeing Board:

Shorter term

1. to adopt the service model as a template for future development of carers services in Sandwell
2. To Develop clear and fair pathways to support for all carers, by
  - a. setting up systems that make it simpler and quicker for carers to speak to the right person and get the right support at the right time
  - b. agencies working together so that carers' needs can be assessed by those who know them best
  - c. making sure that carers always receive the best customer care
  - d. finding ways to give information to carers when they most need it, like when they first become a carer.
3. To invest in more support for young carers and carers of people with dementia
4. To agree a clear policy on short breaks, in line with legislation, so that carers can get breaks when they need them and in an emergency.
5. to review and make clear our charging policies for carers services to make sure they are fair and reasonable
6. to make governance and leadership arrangements for carers stronger.

Longer term

- 2.1 To make it easier to get information about carers' rights and local services via the internet and at key points
- 2.2 To develop a new central carers' 'hub' with one number to call, and a central place to drop in for information and access to all carers' services
- 2.3 To establish better outreach to carers
- 2.4 To develop a new Sandwell Carers' List or register so carers get regular information about services and support, and that tells us about what carers need and the services they use.
- 2.5 To provide more NHS support for carers by building on existing work and investment within primary care.
- 2.6 To make sure that all carers' support workers work together and have a shared way of working that puts carers' wellbeing at the centre of what they do.
- 2.7 To make sure we cover carers' costs (like sitting and travel) when they are involved in developing services
- 2.8 To make sure that carers get support that meets their individual needs. This included more consistent and sensitive assessment, and more tailored support including services for male carers, working carers and black and minority ethnic (BME) carers.
- 2.9 To keep carers involved in - and informed about - changes and improvements.

An **independent review** of many adult and generic carers' services in 2011 concluded that:

- We are almost certainly underestimating (at 3,000) the number of carers currently supported in Sandwell and we need better ways of measuring this.
- The new People Theme in the Council presents a real opportunity to provide more family – based support that has the potential to achieve better outcomes.
- Commissioning and investment arrangements are complex and could be rationalised and improved through a more strategic, long term approach across service areas and partners.
- The existing carers provider forum is a useful forum in which to plan operational changes to support family-based support.
- We should improve operational management and coordination of carers services to deliver better outcomes and value.
- Extend access to carers' services to include evenings and weekends.
- We need to strengthen the focus on supporting carers to maintain or find employment or training.
- We should adopt a consistent way of measuring quality and satisfaction across carers' services.
- We need to develop a clear policy on charging and eligibility for carers' services.
- We should increase uptake by BME carers
- Mechanisms to empower and involve carers should be built into all contracts and service specifications.

The new **Joint Commissioning Plan for Carers** deals with these issues in greater detail and sets how we plan to invest in the next three years. This is set alongside specific commissioning plans for young carers and parent carers that will set out plans for these services.

### **What carers have told us**

*'Not everybody understands...the seriousness and the lifestyle'*

Comment from a young carer: local consultation

*"Why are there so many obstacles in your way to access the simplest services for your loved ones?"*

*"You need a friendly face or a real human voice to ask questions and explore what you need as a carer"*

Comments from 2011 consultation

### **During the 2009 carers strategic review carers said:**

- We may not be reaching all carers who need support, particularly
  - young carers

- carers supporting people with dementia
- 'Hidden' carers
- Older carers: half of all carers
- Working carers – three fifths, 6 out of 10. A third of all carers are working full time
- Carers looking after older people
- Support is great for some but hard to 'navigate'
- The system is not 'carer friendly' enough
- We should involve carers more to make sure services meet their needs
- Some specific areas need development

The **2007 research** on working carers found that, like carers elsewhere in Britain, a sample of 29 of Sandwell's working carers often felt their use of services was limited because:

- Services are **too expensive** (39% compared with 33% of a GB sample).
- They do not like the way services are **organised** (25% compared with 31% of a GB sample).
- There are **no suitable services** in their area (42% compared with 32% of a GB sample).
- Services are **not reliable** (27% compared with 30% of a GB sample).
- Services are **not flexible** (44% compared with 46% of a GB sample).
- Services are **not sensitive** to needs (43% compared with 44% of a GB sample)
- They **do not know what is available** locally (42% compared with 31% of a GB sample).
- The **cared for person does not want to use services** (40% compared with 37% of a GB sample).

During the **consultation on this strategy**, some key messages came from carers:

- **Cuts and the value of carers:** strong views from many people about the potential impact of cuts on carers themselves and on other services if carers cannot cope. Cuts were often seen as a reflection of the council's respect for the contribution carers make.
- **'Double Whammy':** some anxiety among carers about the multiple effects of service changes and reductions on their lives, as they depend on services for the people they look after as well as support for themselves (which they may need more than ever).
- **Personalisation and Assessment:** responses urged us to offer more responsive, personal and flexible services, with more choice but support for families to manage the choices and challenges of new ways of supporting people (especially personal budgets).



- **Access to support:** many carers described difficulties with accessing the support they need at the right time.
- **Engagement and Peer Support:** emphasised the need to communicate well with carers, and involve them positively despite the pressures upon them.
- **Purpose and impact of the Consultation, and Progress/ Change:** a mixture of desire for change that has been discussed for some time to happen in practice; and cynicism about whether comments would make any difference.
- **Existing services:** praise for the support provided by some current services and concerns about their future and whether future services will continue to meet these people's needs

## Conclusions

- Findings of the local strategic review 2009 are broadly supported by other data and research
- Good, reliable up to date local information about carers is difficult to draw together without a register and regular survey of Sandwell's carers between census years.
- There is intelligence about carers that we could use better to reach and support them better – e.g.
  - Carers facing the **greatest risks** to their health and wellbeing are those
    - providing over 20 hours of support a week
    - living with the person they support
    - supporting more than one person
    - whose own health is poor
    - who have no family support
  - **largest number** of carers in West Bromwich: smallest in Tipton;
  - highest percentage of the population caring in Wednesbury: lowest in Smethwick
  - **working carers** are a majority and twice as many male as female carers work full time. In order to reach them better we must provide information and support at evenings and weekends
  - two thirds of **young carers** are supporting someone with a physical disability

## Appendix 2: Carers policy

The body of legislation and guidance relating to carers has significantly grown over the last fifteen years. The following highlights some of particular relevance. There is also legislation and guidance relating to the specific groups of people, for example, Dementia, Adult Mental Health, Learning Disability and Disabled Children etc, which influence our support for carers.

### Section 2: Background

#### National Policy Context

- Carers have specific rights including being consulted and involved in the care planning of those people being cared for, as well as an entitlement to separate assessment for those who provide “regular and substantial care”. It is important to recognise as carers as people themselves with their own needs and aspirations. Assessments should take into account their willingness to continue caring and need to enjoy a life outside of caring. Working carers are also recognised by way of flexible working conditions.
- The primary responsibility for supporting carers lies with the local authority. There is also an expectation that NHS organisations will work in partnership to ensure carers are recognised and receive effective support.
- The national carers strategy sets out the Government’s priority outcomes for carers.

#### ***Carers (Recognition and Services) Act 1995***

- Gave new rights and legal status to carers, defined as individuals who provide substantial amount of care on a regular basis.
- Introduced concept of carers’ assessment, which under this Act is of the carer’s ability to provide and continue to provide care.
- Applies to carers of all ages.

#### ***National Carers’ Strategy 1999***

- Signalled ‘carers’ package’ of information, support and care.
- Included the intention to legislate to give new power to local authorities to provide support for carers. Initial focus on these to be on breaks for carers.
- Good practice in providing for young carers at a local level also highlighted.

#### ***Carers and Disabled Children Act 2000***

- Gave local authorities power to provide services direct to carers, following assessment; also to make direct payments to carers (and disabled children) to meet their assessed needs.
- Gave carers a right to assessment independent of the community care assessment of the cared for person.
- Provides for local authorities to run short-term break voucher

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|   | <p>schemes.</p> <ul style="list-style-type: none"> <li>○ Empowered local authorities to charge carers for services they receive.</li> <li>○ Act applies to carers aged 16 and over, and people with parental responsibility for disabled children.</li> </ul>  |
| <b><i>Employment Act 2002</i></b>   | <ul style="list-style-type: none"> <li>○ Gives working parents of disabled children under 18 the right to request flexible working arrangements. Also confers right to take (unpaid) time-off for dependents in cases of emergency.</li> </ul>   |
| <b><i>Carers (Equal Opportunities) Act 2004</i></b>                                 | <ul style="list-style-type: none"> <li>○ Section 1 outlines good practice on information to carers.</li> <li>○ Section 2 marks major shift in responsibilities of local authorities, from assessing carers in relation to their caring role to requirement to promote their social inclusion. It requires that carers' needs for education, training, employment and leisure are part of the process of assessment.</li> <li>○ Section 3 relates to co-operation between public bodies and seeks to ensure carers are recognised and supported by them.</li> <li>○ Act applies to: <ul style="list-style-type: none"> <li>- carers who provide or intend to provide a substantial amount of care on a regular basis to someone aged over 18</li> <li>- People with parental responsibility for a disabled child, who provide or intend to provide a substantial amount of care on a regular basis for that child.</li> </ul> </li> </ul> |
| <b><i>2000 and 2004 Acts Combined Policy Guidance 2005</i></b>                      | <ul style="list-style-type: none"> <li>○ Updates and supersedes previous guidance on the 2000 Act.</li> <li>○ Advises on content of a carers' information strategy.</li> <li>○ Emphasises that assessments and services for carers should be 'person-centred, seamless and pro-active'. They should focus on positive outcomes and be flexible and imaginative in the ways needs can be met.</li> </ul>  |
| <b><i>The Social Care Institute of Excellence Practice Guidance to 2004 Act</i></b> | <p>Includes model framework of good practice on implementing the Act. Summarises key research and policy findings, practice points and ideas for practice for each of the three sections of the Act.</p>   |
| <b><i>National Framework – Safeguarding Adults</i></b>                              | <ul style="list-style-type: none"> <li>○ Launched in 2005: "Safeguarding adults: a national framework" sets out standards for good practice in adult protection work</li> </ul>  |

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| <b>Work and Families Act 2006</b>   | <ul style="list-style-type: none"> <li>○ From April 2007, extends the right to request flexible working to those who have caring responsibilities for adults.</li> </ul>  |
| <b>Aiming High for Disabled Children (AHDC)</b>   | <ul style="list-style-type: none"> <li>○ Launched in May 2007, AHDC is the transformation programme for disabled children's services. Now superseded by the Early Intervention Programme.</li> </ul>  |
| <b>Carers at the heart of 21st-century families and communities</b><br><b>National Carers Strategy</b><br>June 2008 | <p>Launched in June 2008. The Carers strategy sets out the Government's short-term agenda and long-term vision for the future care and support of carers: <i>'Our vision is that by 2018, carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.'</i> It sets out the government's intentions to achieve certain outcomes for carers by 2018:</p> <ul style="list-style-type: none"> <li>○ Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.</li> <li>○ Carers will be able to have a life of their own alongside their caring role.</li> <li>○ Carers will be supported so that they are not forced into financial hardship by their caring role.</li> <li>○ Carers will be supported to stay mentally and physically well and treated with dignity.</li> <li>○ Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes.</li> </ul> |
| <b>Report of Stranding Commission on carers</b><br>2009   | <ul style="list-style-type: none"> <li>○ The Standing Commission gives carers a voice at the heart of government and scrutinises and supports the delivery of the short and longer-term outcomes set out in the national Carers Strategy. This report concludes the first stage of the Commission's work (December 2007 to June 2009). The report highlights progress against each of the main themes of the strategic vision (as set out in the national Carers Strategy above), and signposts future challenges and opportunities. It also contains recommended actions and suggestions for the Government, delivery partners and the next phase of the Commission.</li> </ul>  |
| <b>Putting people first without</b>   | <p>Discussion document produced by Princess Royal Trust for Carers and Crossroads Caring for Carers.</p>  |

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| <p><b><i>putting carers second 2009</i></b></p>  | <ul style="list-style-type: none"> <li>• Examines challenges faced by local councils and health trusts in making personalisation a reality for carers alongside those they care for.</li> <li>• Highlights a range of solutions already in place to meet those challenges, including inspirational partnerships between Third Sector carers' services and innovative commissioners.</li> </ul>   |
| <p><b><i>Commissioning for Carers 2009</i></b></p>   | <p>Cross agency practical guide to help commissioners to get better outcomes for carers. Key recommendations include:</p> <ul style="list-style-type: none"> <li>○ think 'carer' in all commissioning and area needs assessments</li> <li>○ improve outcomes, independence and choices for both carers and those they care for</li> <li>○ involve carers of all groups and communities in decision-making and planning processes</li> <li>○ strengthen the provider market, using a variety of funding approaches</li> <li>○ meet new NHS and social care inspection expectations and demonstrate that they meet key commissioning competencies.</li> </ul>  |
| <p><b><i>Supporting Carers: Early interventions and better outcomes 2010</i></b><br/>(Association of Directors of Adult Social Services / Princess Royal Trust for Carers)</p> | <p>Association of Directors of Adult Social Services and Princess Royal Trust for Carers . Third in a sequence of short reviews designed to stimulate debate and improve the support for carers. Contains five key messages, supporting policy on personalisation and eligibility for support; highlighting evidence, but pointing to a need for a stronger evidence base around which service users, carers, commissioners and providers can better judge services.</p> <p><b>Key messages:</b></p> <ol style="list-style-type: none"> <li>1. Early intervention is integral to personalisation.</li> <li>2. Applying early intervention thinking to the support of carers can lead to better value for money and better outcomes.</li> <li>3. There is an evidence base to support the claim that carer support can create savings for adult services.</li> <li>4. Considering carer support in the context of major care pathways such as hospital discharge, falls, dementia and stroke could generate systems-wide efficiencies.</li> <li>5. Systematic information collection from service users and carers would improve the evidence base and improve the investment of limited resources in both health and social care.</li> </ol> <p>The elements which every area needs to have in place are:</p> <ul style="list-style-type: none"> <li>• involvement</li> <li>• proactive outreach to carers,</li> </ul> |

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|  | <ul style="list-style-type: none"> <li>• information and advice;</li> <li>• support for carers as care partners</li> <li>• support to plan for their own lives, including emergencies;</li> <li>• targeted support for older people whose carers will also benefit;</li> <li>• emotional, practical and peer support, carer training;</li> <li>• breaks and opportunities in employment and leisure</li> <li>• help to use health and support services which they need themselves;</li> <li>• systematic and regular feedback of the outcomes experienced by users and carers, a real say</li> <li>• share feedback with health, social care and other agencies.</li> </ul>  |
| <p><b><i>Carers and personalisation: improving outcomes</i></b> Nov 2010</p>                       | <p>This document explores personalisation in relation to carers. It provides practical examples for achieving better outcomes through greater involvement, choice, and control for carers and by adopting whole family approaches.</p>   |
| <p><b><i>Recognised, valued and supported: Next steps for the Carers Strategy</i></b> Nov 2010</p> | <p>A cross-Government document which sets out how the Government will prioritise actions over the next four years to ensure the best possible outcomes for carers and those they support.</p> <p>Builds on previous national carers strategy and confirms the new coalition government’s <b>vision</b>:</p> <p>Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals’ needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.</p> <p><b>Outcomes:</b></p> <ul style="list-style-type: none"> <li>• Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.</li> <li>• Carers will be able to have a life of their own alongside their caring role.</li> <li>• Carers will be supported so that they are not forced into financial hardship by their caring role.</li> <li>• Carers will be supported to stay mentally and physically well and treated with dignity.</li> <li>• Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.</li> </ul> |