The Carers Strategy for Wales 2013
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FOREWORD

It gives me great pleasure to publish the refreshed Carers Strategy for Wales. This fulfils a commitment we made to carers in our ‘Programme for Government’. According to the most recent Census there are more than 370,000 people, of all ages, providing unpaid care and support to relatives, friends of neighbours who are disabled, frail or otherwise vulnerable. As a society we owe them a huge debt, and we have a responsibility to ensure that they are themselves supported and are not disadvantaged as a result of their caring role.

The Carers Strategy was last updated in 2007, and significant advances have been made in public policy towards carers since then, including new requirements on the NHS and local authorities under the Carers Strategies (Wales) Measure 2010. Carers will also be granted enhanced rights to support under the provisions of the Social Services and Well-being (Wales) Bill, which is currently before the National Assembly for Wales. This refreshed Carers Strategy draws these and other initiatives together into a coherent framework, so that agencies across Wales can continue to work together to deliver services and support to carers.

There remain significant challenges, with an ageing population and the difficult economic climate increasing the pressure on unpaid carers and those agencies which support them. The need for innovative and sustainable approaches to supporting carers has never been greater. Many new approaches are already being piloted within statutory agencies, the third sector, and by carers themselves. It is my hope that this refreshed strategy will stimulate the further development of services and support for carers of all ages.

I am very grateful to all the carers and others who have helped to develop the Carers Strategy through responding to the consultation and in other ways. We have listened to what you had to say, and have tried to structure the strategy around your needs and priorities. I look forward to working with you in future as we move into its implementation.
Summary

In its Programme for Government for 2010-15, the Welsh Government gave a commitment to refresh its Carers Strategy for Wales. Much has been achieved in terms of policy, legislation and service development for carers since the strategy was last reviewed in 2007, and this refreshed strategy provides a framework within which agencies across Wales can work together to deliver services and support to carers, promote and share good practice, and find innovative and sustainable ways of supporting carers more effectively. The strategy will cover carers of all ages.

Chapter 1 of this document sets out the outcomes we want to achieve for carers in Wales.

Chapter 2 summarises what has been achieved so far, including the key legislative milestones and the lessons learned from implementation of the original Carers Strategy and 2007 Action Plan.

Following consultation with stakeholders, the Welsh Government has decided that the refreshed strategy should continue to address five key priority areas, which are broadly the same as those in the original Carers Strategy for Wales. They are:

- health and social care
- identification, information and consultation
- young carers and young adult carers
- support and a life outside of the caring role
- carers and employment.

Chapters 3 to 7 explore each of these key priority areas in turn, and contain the actions the Welsh Government intends to take to achieve positive outcomes for carers.

Chapter 3 sets out in broad terms the measures we will be putting in place through the Social Services and Well-being (Wales) Bill to strengthen carers’ rights, and discusses the promotion of carers’ health and wellbeing. This recognises the key role of primary health care (especially GPs) in identifying carers and referring them to appropriate sources of advice and support; and makes links with the mental health strategy for Wales (‘Together for Mental Health’).

Chapter 4 focuses on implementation of the Carers Strategies (Wales) Measure, which placed a new duty upon the NHS and local authorities in Wales to work in partnership to prepare, publish and implement local Information and Consultation Strategies for Carers. These local strategies set out how information will be provided to carers, to assist them in carrying out their caring role more effectively; and set out how carers will be consulted and involved in decisions affecting them and those they care for. This is supported by significant implementation funding from the Welsh Government from 2012-13 to 2015-16.
Chapter 5 responds to what young carers up to the age of 18 have told us are their main concerns. It also recognises the ongoing needs of young adult carers aged 18 to 25.

Chapter 6 deals with the important issue of ensuring that all carers get the breaks they need from caring, and are supported in accessing lifelong learning, recreational and leisure opportunities. It proposes developing a shared understanding of ‘alternative care’ within the context of the Social Services and Well-being (Wales) Bill, to help carers achieve positive outcomes.

Chapter 7 recognises the needs of carers who work or wish to move into work. The key to carers retaining or accessing employment is flexibility, and a priority of this chapter is to promote flexible approaches that meet the needs of employers and of those employees who are carers. Although many issues around employment are non-devolved, the Welsh Government will be able to promote best practice within the public and private sectors in Wales.

The strategy sets out the key actions the Welsh Government intends to take for the remainder of this Assembly Term, up to 2016. These actions will be delivered through a more detailed delivery plan covering the period up to the Assembly Elections in 2016, which will be reviewed regularly. This will be developed through further engagement with stakeholders and published by the end of 2013.
Chapter 1

Introduction: achieving positive outcomes for carers

1.1 A carer can be anyone, of any age, who provides unpaid care and support to a relative, friend or neighbour who is disabled, physically or mentally ill, or affected by substance misuse. Unpaid carers are the single largest provider of care to people with support needs in our communities, and they save the NHS and social services millions of pounds a year.

1.2 The Social Services and Well-being (Wales) Bill (2013) defines a ‘carer’ as a person who provides, or intends to provide, care for an adult or disabled child. It excludes those who provide care under or by virtue of a contract or as voluntary work. The definition includes carers of all ages.

1.3 Children and young people who provide care and support for a parent, sibling or other relative are usually called young carers. Carers aged 18 to 25 are often referred to as young adult carers. Parents who provide care for a disabled or sick child (where there are care and support needs over and above ordinary parental support) are called parent carers. This strategy covers all categories of unpaid carers in Wales.

1.4 The past twenty years have seen a much greater awareness among the general public, politicians, and those who plan and commission services of the role played by unpaid carers. There is a greater recognition of the need to support these carers and the advantages of doing so. With increasing numbers of older people, and increasing pressure upon public services, there are clear social and economic benefits to enabling carers to continue in their caring role.

1.5 It is vitally important that these unpaid carers are themselves supported and are not disadvantaged as a result of caring. Support to carers is provided by many different agencies including health and social services, third sector organisations, education and training providers, and employers.

1.6 The Carers Strategy for Wales was originally published in 2000, a year after devolution. An updated Action Plan was published in 2007. Much has been achieved in terms of policy, legislation and service development since then, including implementation of the Carers Strategies (Wales) Measure 2010. The next few years will see further significant changes in the way support is provided to carers and those they care for, as a result of the Social Services and Well-being (Wales) Bill currently being considered by the National Assembly for Wales.

1.7 This refreshed strategy provides a framework within which agencies across Wales can work together to deliver services and support to carers, promote and share good practice, and find innovative and sustainable ways of supporting carers more effectively. It also sets out the actions the Welsh Government is taking to support these regional and local partners in delivering better outcomes for carers.
Carers in Wales

1.8 Reliable information on the number and characteristics of carers in Wales is limited. It can be difficult to determine at which point providing assistance to a relative or friend becomes a caring role. Many people do not see themselves as carers, but simply as a spouse, partner, neighbour or friend. Also, each caring situation will be different. The pattern of caring in each case will be shaped by family and other relationships and circumstances, and by the capabilities, needs and preferences of the carer and the person being cared for. Nonetheless, there is a need for reliable research and statistical data on carers to inform the planning and delivery of services and support. Implementation of the Carers Strategies (Wales) Measure 2010 should lead to more carers being identified and recorded at local level by health and social services.


1.10 The 2011 Census shows there are 370,230 people providing unpaid care in Wales, representing 12.1 per cent of the population (for England and Wales taken together the figure was 10.3 per cent). Since 2001, there has been an increase of approximately 30,000 people providing unpaid care in Wales, representing an increase of 3 per cent in the proportion providing care. The growth in unpaid care was highest in the 50 hours or more category – in 2011, 103,748 people in Wales fell into this category.

1.11 The local authority with the largest percentage of its population providing unpaid care was Neath Port Talbot, at 14.6 per cent. Cardiff had the lowest at 10.1 per cent, which is probably due to its younger age structure. The more rural authorities, such as Monmouthshire and Carmarthenshire, saw the greatest percentage increases, while the traditional industrial heartlands of the Valleys remained largely static with an eighth to a seventh of their populations providing some level of unpaid care.

1.12 All unitary authorities in Wales had an increase in the absolute number of carers compared with 2001. This is due partly to population growth. In Cardiff, although there was a slight fall in the percentage of the population providing unpaid care, absolute numbers increased the most.

Outcomes for carers

1.13 The key outcomes we want to achieve for carers are:

- carers are appropriately identified, and receive the right information at the right time and in appropriate formats
- carers are listened to, treated with respect and achieve proper recognition
• carers are not disadvantaged or discriminated against as a result of taking on a caring role
• carers are genuinely involved in all decisions that affect them and the people they care for, including decisions about the level of care they are willing and able to provide
• carers are consulted and involved in the strategic planning, delivery and evaluation of health, social care and other relevant services
• carers’ needs are appropriately assessed and met
• carers receive timely and appropriate practical and emotional help, support and training
• carers are supported in maintaining their own health and well-being
• carers are able to maintain as normal a life as possible, are enabled to have a life outside of the caring role, and are supported when the caring role ends
• carers are able to access employment, education and training, and leisure opportunities.

These outcomes apply to carers of all ages. In addition, a key outcome for young carers up to age 18 is:

• young carers are enabled to enjoy their rights under the United Nations Convention or the Rights of the Child, and all agencies which support them will give due regard to these Convention rights.

1.14 The Welsh Government is working with key partners to develop a National Outcomes Framework, supported by high-level and measurable indicators, for social services and social care. We will ensure that the outcomes for carers listed here are taken into account as the work to develop that Framework progresses.

1.15 In achieving these outcomes for carers, due consideration must be given to the needs of carers with protected characteristics under the Equality Act 2010. It is also Welsh Government policy that services and support for older carers (and older people who are cared for) should take account of the United Nations Principles for Older People.

1.16 We would also wish to see appropriate provision of information, advice and support across Wales to carers whose first or preferred language is Welsh.
Chapter 2

What has been achieved so far

2.1 In the years following devolution, successive Welsh Governments have put in place a significantly strengthened and expanded policy and delivery framework of support to carers. This chapter sets out some of the key milestones.

Key legislative milestones

2.2 Key legislative milestones since the publication of the Carers Strategy include the following.

- The Carers and Disabled Children Act 2000 came into force in Wales in July 2001. This Act gives local authorities power to supply services directly to carers following assessment, and to make direct payments to carers for services that meet their own assessed care needs.

- The National Health Service Reform and Health Care Professions Act 2002 (now contained in the National Health Service Act 2006) placed a duty on each local authority and local health board to formulate and implement a Health and Well-being Strategy for the public in the local authority area.

- The Carers (Equal Opportunities) Act 2004 came into force in Wales in April 2005. This Act places a duty on local authorities to inform carers of their right to an assessment, and requires carers’ assessments to consider whether the carer works or is undertaking education, training or any leisure activity, or wishes to do these things. The Act also provides for better co-operation between statutory agencies in the provision of services for carers.

- The Work and Families Act 2006 came into force in Wales in April 2007. This Act widens the scope of the existing law on flexible working to enable more people with caring responsibilities to request to work flexibly.

- A landmark ruling by the European Court of Justice in 2008 in the ‘Coleman’ case established that the UK’s disability discrimination law provides protection on the grounds of someone’s association (including caring responsibilities) with a disabled person. This case helped extend legal protection in the workplace to carers and others who associated with protected groups. The Equality Act 2010 extended this protection (see 2.12 to 2.15).

- The Community Care, Services for Carers and Children’s Services (Direct Payments) (Wales) Regulations 2011 extended direct payments to people who are unable to consent to them. In these circumstances the payments are made to a designated ‘suitable person’, who in many cases will be the carer. This means that the
Carer has more choice and control over the care arrangements to meet the assessed needs of the person who is being cared for.

- Under the Carers Strategies (Wales) Measure 2010, Local Health Boards, working with their partner local authorities, were required to develop and implement Carers Information and Consultation Strategies by October 2012. This was one of the first pieces of legislation passed in Wales after the National Assembly for Wales was awarded powers to make primary legislation. Further details of the Measure may be found in Chapter 4.

- The Breaks for Carers of Disabled Children (Wales) Regulations 2012 came into force on 28 June 2012. The Regulations require local authorities to: ensure that, when making short break provision, they have regard to the needs of different types of carers, not just those who would be unable to continue to provide care without a break; provide a range of breaks, as appropriate, during the day, night, at weekends and during the school holidays; and provide parents with a short breaks services statement detailing the range of available breaks, and any criteria by which eligibility for services will be assessed.

- The Mental Health (Wales) Measure 2010 recognises the importance of involving carers in the planning, development and delivery of care to all those receiving mental health services.

- The Social Services and Well-being (Wales) Bill 2013 contains provisions to transform the way social care and well-being services are delivered to carers and those they care for. The Bill is expected to be enacted in 2014, and implementation will begin in 2016.

Funding for Carers

2.3 Implementation of the Carers Strategy 2000 was supported by pump-priming money to encourage innovation in providing flexible services for carers. Originally available for three years and subsequently extended until 2005-06, it was then incorporated into the annual Revenue Support Grant which local authorities receive from the Welsh Government.

2.4 From 2006-07 another specific grant scheme – the Mental Health Support Grant – was introduced to develop services to support carers for people with mental health problems. This, in turn, was incorporated into the Revenue Support Grant from April 2010.

2.5 Throughout the period, significant grant funding has been made available to national voluntary organisations working with carers, under the ‘Section 64 General Scheme’ and other grant schemes. £1.46 million has been awarded to carers organisations under the ‘Section 64’ scheme for the current three-year funding round (2012-13 to 2014-15).

2.6 In addition, the Welsh Government provides grant funding of £10,000 a year to the Wales Young Carers Network, which brings together young carer representatives
from each of the local young carers projects in Wales. The network has an annual meeting with the Deputy Minister for Social Services, at which young carers’ concerns are raised directly with the Welsh Government.

2.7 The Welsh Government has provided significant funding to local health boards and NHS trusts to develop and implement their Carers Information and Consultation Strategies. Initially for the three years 2012-13 to 2014-15, the funding will now be extended into a fourth year (2015-16) so that local partners can ensure a smooth transition to the new arrangements which will be put into place in 2016 under the Social Services and Well-being (Wales) Bill. Overall, the funding will total £4.265 million.

Evaluation of the Carers Strategy

2.8 The Welsh Government commissioned a formal study of the Carers Strategy from Bangor University, the findings of which were published in July 2010. The study was based on interviews with carers and statutory and voluntary sector staff over a five year period (2003-08). Overall, the report was relatively positive about the impact of the Carers Strategy, concluding that it had promoted organisations to reconsider the ways in which carers are supported and to begin to develop new types of services and support. It noted also that legislative changes relating to assessment of carer need were reported to have had a positive effect on the commissioning and delivery of services.

2.9 The report found evidence of an increasing commitment from staff to embrace more outcome-focused approaches, seeing carers as service users in their own right. However, there may be a lack of shared understanding of the caring experience, resulting in a considerable gap between the policy commitment to deliver individualised support to carers and carers’ everyday experiences.

2.10 The authors say that their findings:

… highlight a gap between the positive perceptions of staff concerning improvements in the availability and types of support to carers and carers’ everyday experiences. Whilst staff suggested that the Carers Strategy has encouraged the development of innovative services that broaden the parameters of support to carers, this was not always reflected in carers’ experiences. Staff highlighted changes to the carer assessment process that specify carer-defined outcomes must be made explicit as having had a positive effect on the commissioning and delivery of new services. However, only a limited number of carers were in receipt of these services and they reported problems relating to their organisation and delivery.1

2.11 The authors suggested that the contrasting conclusions of carers and staff highlighted ‘the considerable scope for expanding and improving service provision for carers and building upon the progress achieved to date’.
Promoting equality and inclusion for carers

2.12 The Equality Act 2010 provides protection from discrimination on the grounds of nine ‘protected characteristics’. Although caring is not itself a protected characteristic, carers who are looking after someone with a protected characteristic (such as disability or age) are protected from direct discrimination or harassment by means of their ‘association’ with that person. For details of how the Act affects carers, see the UK Government Equalities Office guide, *Equality Act 2010: What do I need to know as a carer?* [https://www.gov.uk/government/publications/equality-act-guidance](https://www.gov.uk/government/publications/equality-act-guidance).

2.13 Regulations made under the Equality Act introduced Wales specific equality duties, which came into force in April 2011. The duties outline the steps which public authorities in Wales must take to advance equality, eliminate unlawful discrimination, and foster good relations. These include duties to undertake an equality impact assessment of policies and practices, to engage widely and to draw on robust evidence. In April 2012 the Welsh Government published its Strategic Equality Plan, setting out its priorities for action to fulfil the general duties in the Equality Act and the Wales specific equality duties.

2.14 The Strategic Equality Plan includes objectives to strengthen advice, information and advocacy services; tackle barriers and support disabled people so that they can live independently and exercise choice and control in their everyday lives; and put the needs of service users at the heart of delivery in key public services. Local health boards and local authorities in Wales have also published their own Strategic Equality Plans, and are required to publish annual reports showing their progress in achieving their equality objectives and the Public Sector Equality Duties. This new framework for equality in Wales should directly benefit carers and those they care for.

2.15 Carers will also benefit from the Welsh Governments’ Framework for Action on Independent Living,’ which is due to be published in Summer 2013. The framework specifically aims to support disabled people to live independently by tackling the barriers they face to full participation in society, leading to more inclusive communities and services which will also be of benefit to carers, families and society as a whole.

**Sustainable Development**

2.16 The Welsh Government is committed to acting in the long term interests of the people of Wales, and to ensuring a decent quality of life for everyone. This principle will be set out in the duty we propose to place on ourselves, and on organisations providing public services for the people of Wales. The proposed Sustainable Development Bill confirms the long term direction for Wales, in that we seek a fair balance between the pressing short term needs and the long term interests of people. We will consider the social, economic and environmental factors that are so important for people's long term quality of life. The Carers Strategy for Wales sets out how this principled approach will be applied to improving the quality of life for carers, who are a vital and valuable part of society in Wales.
Developing the refreshed Strategy

2.17 In April 2012, the Deputy Minister for Social Services set up an Advisory Group of key stakeholders from carers organisations, health, social services and education to reflect upon the lessons learned from implementation of the original strategy and Action Plan, to consider the priorities for taking the strategy forward over the next three to five years, and to identify key actions.

2.18 The draft refreshed strategy was published for consultation in November 2012. A summary of the consultation responses may be found on the Welsh Government’s website at:
http://wales.gov.uk/consultations/healthsocialcare/carersstrategy/?status=closed&lang=en

2.19 The Welsh Ministers would like to thank the members of the Advisory Group, and all who responded to the consultation, for their constructive contributions which have helped to shape the final version of this strategy.
Key Priority Areas

We have identified five key priority areas for action in taking forward this strategy:

- health, social care and well-being
- identification, information and consultation
- young carers and young adult carers
- support and a life outside of the caring role
- carers and employment.

The following chapters address each of these priority areas in turn, and set out the key actions the Welsh Government intends to take for the remainder of this Assembly Term, up to 2016.
Chapter 3

Health and social care

Sustainable social services for carers

3.1 ‘Sustainable Social Services in Wales’ (February 2011) set out the Welsh Government’s vision for transforming social care in Wales. This means developing social services that are high quality, responsive and citizen-centred. At the heart of this is the need to ensure that citizens have a stronger voice and real control. As the single largest provider of care to people with support needs in our communities, the unpaid care workforce should be central to this transformational agenda for social care.

3.2 An important first step will be putting in place a new legal framework to bolster carers’ rights. The Welsh Government introduced its Social Services and Well-being (Wales) Bill in January 2013. The provisions in the Bill are expected to be implemented in 2016.

3.3 The Bill provides carers, for the first time, with equivalent rights to the people they care for. It includes measures to ensure that local authorities and local health boards:

- understand the characteristics and needs of their local population including carers
- provide or arrange the provision of a range and level of services including preventative services to carers which are accessible within the community
- ensure that carers can readily access information, advice and assistance about the type of support and services available in their community and to help them to understand how the care and support system works.

3.4 At an individual level carers will:

- have a right to an assessment of their needs for support without the need to formally request an assessment. A local authority’s duty to assess will be triggered where it appears that the carer may or will have needs as part of their caring role
- have a right to support where their need is one that meets with eligibility criteria to be set out in Regulations
- where they have eligible needs, have a statutory support plan that the local authority must regularly review.

3.5 The Bill provides a single right to an assessment for children, adults and carers based on an individual’s need for care and support and the outcomes the individual wishes to achieve. The aim is to create a system for assessment and
eligibility for users and carers which is more consistent across Wales; is understandable, transparent and outcome-focused; supports prevention; and continues to allow local authorities to respond flexibly to individual, family and local circumstances.

3.6 The single right to an assessment will apply to adult carers, young carers and parent carers. This replaces the existing law, and removes the requirement that the carer must be providing ‘a substantial amount of care on a regular basis’. This will mean more carers are able to access an assessment, and that the duty is comparable to that for the people they support.

3.7 When the carers’ assessment is complete, the local authority must determine what their support needs are and whether those needs are eligible for support. The local authority must use an eligibility framework, to be set out in Regulations. These Regulations will provide a new framework for determining eligible needs for carers, alongside the approach for the people they care for.

3.7 The Bill makes a distinction between adult carers and child carers (young carers) to take account of particular issues raised by children and young people acting as carers.

3.8 Local authorities will also have duties to provide and keep under review support plans for carers who have eligible needs. This is in order to promote consistency between plans for carers and plans for people with needs for care and support.

3.9 The Welsh Government is working with local authorities and partners, including those representing carers, in developing the new integrated assessment framework and tools necessary to support the delivery of the new model of care and support.

3.10 To ensure that the changes brought about by ‘Sustainable Social Services’ are effective, the Welsh Government is working with key partners to develop a National Outcomes Framework, supported by high-level and measurable indicators, for social services and social care. Every part of the social care system, including local authorities, service providers and individual practitioners, will be expected to contribute to achieving these agreed outcomes.

**Promoting carers’ health and wellbeing**

3.11 Research commissioned by carers organisations suggests that caring can have a detrimental impact on the physical, emotional and mental health of carers, especially on older carers. The Carers Strategy Action Plan 2007 contained a commitment to monitor on an annual basis the data from the Welsh Health Surveys to assess the impacts on carers’ health. Periodic Statistical Bulletins have been produced by the Welsh Government. In April 2013, the Welsh Government published information based on the latest Welsh Health Survey (2011), to complement this refreshed Strategy. The key findings are summarised below.
• In general, carers aged 16-44 tended to report poorer health (especially mental health) than non-carers of the same age.
• However, older carers aged 65 and over were generally more likely to report slightly better health than non-carers of the same age.
• Carers aged 16-44 were more likely to report smoking or being overweight or obese than non-carers of the same age. There was little difference for the older age groups.
• Carers aged 65 and over were more likely than non-carers to report eating at least five portions of fruit or vegetables a day, and to be physically active on five or more days a week.
• Non-carers aged 65 and over were more likely than carers to have used hospital services (such as attending casualty, or attending an inpatient or outpatient department).


3.13 Early identification can help health services to pro-actively support carers to look after their own physical and mental health needs. This support may take the form of health checks and preventative programmes, information on dietary health, signposting and referral to appropriate agencies who can offer peer and emotional support as well as support to carers to access recreational and leisure opportunities and breaks from caring. There is, unfortunately, little research data on what really makes a difference to carers’ health, especially what services and support works best in practice. Research has shown that for most carers the first point of contact with any statutory agency is within a primary care setting, either at a health centre, GP practice or at home.

Primary care

3.14 The important role of primary health care is acknowledged in the guidance on the Carers Strategies (Wales) Measure 2010 issued to local health boards, NHS trusts and local authorities in December 2011. Development and implementation of local Carers Information and Consultation Strategies should strengthen GPs’ role in identifying carers and referring them to appropriate sources of information, advice and support.

3.15 The Quality Outcomes Framework (QOF) for GPs includes an indicator which requires the practice to have a protocol for the identification of carers and a register for the referral of carers for social services assessment. The QOF guidance also mentions referral to other local support such as a carers centre. 98.4% of practices achieved this requirement for 2009-10. Local health boards are required to assess the delivery of the QOF. The assessors should include actions that would be taken by team members when they identify that a carer may benefit from social services involvement. Implementation of the local Carers Information and Consultation Strategies should assist the local health boards’ Directors of Primary Care and Mental Health in determining the effectiveness of such arrangements.
3.16 In addition, there are award or accreditation schemes to encourage GP practices to develop and implement best practice in relation to carers. These include the ‘Investors in Carers’ accreditation scheme which is being rolled out within the Hywel Dda Local Health Board area, and the ‘Supporting Carers’ toolkit developed by the Royal College of GPs. We will use this Strategy to promote initiatives such as these.

**Investors in Carers GP Practice Award Scheme**

This award-winning scheme was originally created in 2006 by Ceredigion Social Services, Ceredigion Local Health Board and the voluntary sector Carer Support Service. It was extended into Carmarthenshire and Pembrokeshire after being adopted by the Hywel Dda regional partnership in 2010, with additional county-based funding and a grant from the Rural Health Innovation Fund.

The award is based on a series of standards forming an accredited award framework, based on a portfolio of evidence. To achieve the first level of accreditation – the Bronze Level Award – GP practices have to demonstrate that they have processes in place to identify carers and provide appropriate information and signposting to further support. The Award operates as a self-assessment process, based on a portfolio of evidence which is assessed by a panel against a scoring matrix. By July 2012, 49 of the 55 GP Practices across the Hywel Dda Local Health Board region had achieved the Bronze Level Award.

The Silver Level Award has been piloted by 3 GP Practices, prior to roll out across the Hywel Dda region. In addition, 9 pilot sites have been identified for the Investors in Carers Bronze Award Scheme for secondary care services. The copyrighted CD-ROM of the Investors in Carers toolkit materials for the Bronze Level Award has been purchased by six other counties including one in England.

The Investors in Carers scheme is a flexible and transferable framework, which can also help deliver additional carer support services such as carer outreach sessions at GP surgeries or carer support groups. The scheme complements ongoing work within the Hywel Dda Local Health Board to include ‘Carer Aware’ training within the professional development programme for GPs and other health professionals.

Further information may be found at: www.wales.nhs.uk/sitesplus/862/page/57866 or by contacting: Peter Llewellyn, Assistant Director of Strategic Partnerships, Hywel Dda Local Health Board (01437 771257)
Supporting Carers: An action guide

In October 2011, the Royal College of General Practitioners, in conjunction with the Princess Royal Trust for Carers, launched a revised edition of the best practice guide ‘Supporting Carers: An action guide for general practitioners and their teams’. The action guide offers advice on identifying carers, understanding their needs and involving them in the planning of care, along with real-life case studies and practical tools to help practice teams in their work.

First produced in 2006, it has been comprehensively revised and updated to provide GPs with the latest information and knowledge they need to deliver the best possible support to carers in their caring role, and ensure that the individual health and wellbeing needs of both patient and carer are met.

The new-look guide highlights the physical, psychological and other effects of caring that GPs and their teams can look out for, along with specific sections on life after caring, and how to identify and meet the health needs of young carers and young adult carers.

The guide may be downloaded via the following link: http://professionals.carers.org/health/articles/carers-in-practice-rcgp,1792,PR.html

The Royal College also runs an annual UK-wide ‘Caring about Carers’ Award where patients can nominate their GP or GP practice for the care and support received.

Mental health

3.17 For many, mental ill health remains hidden, and sufferers, their families and carers can all too often experience stigma and discrimination. The fact that treatment of a severe and enduring mental illness, such as schizophrenia or bipolar disorder can sometimes, but rarely, necessitate compulsory treatment and detention can sometimes lead to tensions, conflicts and feelings of guilt within the family. Those with a serious mental illness can be vulnerable and often have highly complex needs. Symptoms may be episodic, and it is often the carer or family member who notices a person is becoming unwell and in need of more support, care and treatment than usual. It is therefore extremely important for health and social care professionals to take the views of carers and families into account whenever possible. There are also significant issues for those carers supporting family members and friends with mild to moderate mental health problems, when stress and anxiety can also be significant and long-term. Carers should not feel ignored or excluded and there should be active engagement by professionals and clinicians, especially when a person is due to be admitted or discharged from hospital, and when individuals ask that carers are provided with a copy of their Care and Treatment Plan.
3.18 The Mental Health (Wales) Measure 2010 was designed to improve support for people with mental ill-health in Wales, through the development of modern, user-focused care. It seeks to develop mental health services at the primary care level, expands in-patient advocacy, and introduces secondary service self-referrals. All patients in secondary services will have a Care and Treatment Plan, which will take into account the views of the patient and any carers throughout the process of design and ongoing review. This process will ensure the individual’s wider needs that might affect one’s mental health (the eight areas of life, including housing, employment, physical health, education and parenting, family and caring responsibilities) are taken into account.

3.19 ‘Together for Mental Health,’ the Welsh Government’s mental health strategy, which was launched in October 2012, sets out a new approach to mental health service delivery and wider wellbeing. It combines existing policy, consolidates progress to date and has the Mental Health (Wales) Measure 2010 at its heart. It recognises that there are a range of factors which impact on a person’s mental health, and that this requires a holistic response from Government and a variety of statutory and third sector agencies. This includes not only health and social services, but also education, housing, leisure services, justice agencies and others. ‘Together for Mental Health’ emphasises that the service user and any carers must be placed at the heart of service delivery and design. It recognises that the wellbeing and mental health needs of carers themselves must be addressed; also that many people with mental ill health problems themselves have caring responsibilities.

3.20 ‘Together for Mental Health’ acknowledges that carers of all ages must be provided with all the support they need to fulfil this role, including information, training, financial and emotional support and breaks from their caring responsibilities. An absence of support can have a marked and detrimental impact on a carer’s wellbeing, and this is especially true for young carers and young adult carers who might be caring for a parent with mental ill-health.

3.21 An ageing population also brings challenges of caring for an increased number of people living with dementia. It is estimated that by 2021 the number of people with dementia across Wales will increase by 31%, and by as much as 44% in some rural areas. 1 in 3 people will end their lives with a form of dementia, 1 in 5 people over the age of 80 presently has dementia, and two-thirds of those with a dementia diagnosis live in the community. The vast majority of these people will wish to live with or near their family and carers.

3.22 The Welsh Government published its ‘National Dementia Vision’ in 2011, setting out its long-term ambition of creating ‘dementia supportive communities’ – communities which have the capacity, understanding and sensitivity to support people affected by dementia so that they and their carers can enjoy the best possible quality of life. These are to be achieved through, for example, improved access to information and support for people with a dementia and their carers, and training for those delivering care. The Welsh Government has awarded the Alzheimer’s Society £150,000 to develop and distribute Dementia Information Packs for those with a diagnosis, their families and carers; and the Dementia Services Developmental Centre has been awarded £250,000 to review, develop and deliver training to carers,
staff in care homes, those working in the hospital, community and mental health service settings, and primary care staff, including GPs. The Together for Mental Health Delivery Plan (2012-16) commits the Welsh Government and its partners to improving support for people with dementia, including raising public awareness and understanding of issues associated with mental health and wellbeing in older age, and ensuring that staff across the wider workforce recognise and respond to signs and symptoms of mental illness and dementia.

Older carers

3.23 The Welsh Government published the third phase of the ‘Strategy for Older People’ in May 2013. Consultation on that strategy showed that support for carers remains a major concern among older people. Caring responsibilities can impose significant barriers to the participation of older people in society, and have a negative impact upon older people’s general well-being. Areas of particular concern were:

- the need for older carers to have more regular breaks from caring, recognising that older carers tend to tire more easily than young carers and may not have the physical stamina to care for long periods

- support for older people to have a life outside the caring role - for example, to enjoy some of the things they had planned for their retirement and to have a fulfilled old age

- the need to support older workers who take on caring responsibilities - having to give up work to care can have significant financial consequences for older people.

3.24 These concerns link with two key areas of this strategy: support and a life outside of the caring role, and supporting carers in employment. In taking forward these two areas, we will consider particularly the needs of older carers.

Substance misuse

3.25 The Welsh Government’s Substance Misuse Strategy, ‘Working Together to Reduce Harm 2008–2018,’ contains a number of initiatives aimed at supporting carers and families who are affected by substance misuse. We report on our progress annually through the Substance Misuse Annual Report, the latest of which was published in 2012. There are increasing examples where providers and commissioners work closely with families and carers of those who misuse substances, providing advice, guidance and counselling. The Welsh Drug and Alcohol Helpline (DAN24/7) provides carers and families of substance misusers with easily accessible, accurate information and at the same times signposts to local agencies providing help and support.

3.26 The Welsh Government’s commitment to supporting carers and families of those who misuse substances has been reinforced in the Substance Misuse Delivery Plan 2013-15, published in February 2013. The plan includes a number of commitments.
By October 2013, all area planning boards (which are coterminous with local health board areas) will have an outcome-based commissioning strategy in place. As part of this exercise we expect that the needs of families and carers of substance misusers are assessed and that appropriate services and support are put in place.

area planning boards will also be expected to work with partners to ensure improvements in access to family support services for those identified as in need.

The Welsh Government will work to improve access to support services for families and carers of people who misuse substances through implementation of the Carers (Wales) Measure 2010, and have charged each area planning board to map the extent to which they have fully embedded the requirements of the Carers Measure into service delivery by December 2013.

Key actions

The Welsh Government will:

- legislate for enhanced rights for carers through the Social Services and Well-being (Wales) Bill
- work with carers to develop a new national eligibility framework supported by an integrated assessment process
- promote recognised toolkits that promote improved standards for carer support within GP practices
- ensure that carers continue to be included in health, social care and other relevant policies and strategies such as ‘Together for Mental Health’ and ‘Working Together to Reduce Harm’.
Chapter 4

Identification, information and consultation

4.1 Early identification is key to ensuring that carers get the information, advice and support they need to continue in their caring role. Many carers are still not known to health, social services or other support agencies. Many people with caring responsibilities do not identify themselves as carers, as they see their primary role as that of spouse, partner, neighbour or friend. We will use this strategy to promote better identification of carers, including self-identification.

4.2 For most carers, the first point of contact with any statutory agency is within a primary care setting, either at a health centre, the doctor’s surgery or at home. Carers can also be identified when the person cared for is admitted to hospital; and carers will also need to be engaged when the cared for person is discharged back home. The NHS therefore has a crucial role to play in identifying and engaging with carers, and in signposting or referring them to appropriate sources of support.

4.3 Social services already have clear responsibilities in relation to carers, including identifying the contribution of carers when assessing a person’s needs for care and support, and in undertaking carers assessments. These responsibilities will be strengthened as a result of the provisions contained within the Social Services and Well-being (Wales) Bill.

4.4 Schools and colleges also have an important role in supporting young carers, and are often where children and young people with caring responsibilities are first identified.

4.5 It is important, therefore, that we raise awareness of carers among professionals in health, social care and education, so that they can identify carers as early as possible and know how to respond to their needs.

4.6 It is also important that carers receive appropriate information and advice when they need it and in an appropriate format. Carers need to know their rights and where to go for advice and support; they need information about specific health conditions such as dementia, or how best to perform certain tasks; and they need information to support their own health and well-being. Such information needs to be sensitive to the carer’s age, culture, language and family circumstances. And it needs to be up-to-date, relevant and timely. It can be provided in a variety of settings and formats – including, for example, websites or leaflets, informal peer support groups, or structured training courses.

4.7 Carers also need to be consulted and engaged in every decision that affects them and the people they care for. This includes decisions about their own caring role, and also more strategic decisions about the planning, delivery and evaluation of local support services.

4.8 It was to address these key issues of identification, information and consultation that the Welsh Government introduced the Carers Strategies (Wales) Measure 2010.
Carers Information and Consultation Strategies

4.9 The Measure required the seven local health boards in Wales to work with their partner local authorities and local carers to develop and implement local Carers Information and Consultation Strategies. A similar requirement was placed on the Wales Ambulance Trust and the Velindre NHS (cancer services) Trust. The Measure deliberately placed the lead responsibility upon the local health boards and NHS trusts, in recognition of the crucial role the NHS plays in identifying carers. This was the first time a specific legislative duty had been placed on the NHS in relation to services for carers, and was designed to bring about a culture change in the way NHS bodies in particular engage with carers.

4.10 The Carers Information and Consultation Strategies set out:

- how information, advice and training will be provided to carers, to help them carry out their caring role effectively
- how carers will be consulted and involved in decisions affecting them and those they care for
- the awareness raising and training that will be provided to NHS and local authority staff to help them identify carers and signpost or refer them to appropriate information, advice and support.

4.11 The strategies cover carers of all ages, but it was a requirement that each also had a dedicated chapter and actions dealing with young carers.

4.12 There was widespread consultation and engagement with carers and carers organisations as the strategies were developed during 2012; and carers will continue to be actively engaged in monitoring, review and evaluation as the Strategies are implemented from 2013-14.

4.13 To assist with longer term monitoring and evaluation of the Measure, the local health boards and local authorities have developed an Outcomes Framework to measure the impact the strategies are having on carers’ lives. A Strategic Carers Measure Group has been set up to ensure that the Measure and the Outcomes Framework are implemented consistently across Wales. The Welsh Government will also establish a monitoring and evaluation group to measure success.

4.14 The Carers Strategies (Wales) Measure will eventually be superseded by the provisions within the Social Services and Well-being (Wales) Bill, which will be implemented in 2016. By then, good practice around identification, information and consultation should be well-embedded within the NHS, and enduring partnership arrangements will have been put in place.

4.15 The Bill gives carers equivalent rights and entitlements to the people they care for, and local authorities, facilitated by local health boards, will be required to provide information, advice and assistance to carers of all ages. It introduces, as a statutory requirement, a new Information, Advice and Assistance service, which will be a first point of contact where individuals can access a range of information and
advice on services provided locally by local authorities, the NHS, third sector organisations and user and carer-led support groups. Staffed by skilled professionals, the new service will (where appropriate) seek to provide a tailored response to members of the public and to professionals. The Information, Advice and Assistance service will play an important role in signposting and assisting carers and others in accessing preventative care and support services accessible in the community without the need for formalised assessments. In doing so, it will draw upon the information and resources produced for carers through the Carers Information and Consultation Strategies, and further develop the signposting and referral pathways which partners have established.

4.16 The Welsh Government will continue to monitor how the progress made through implementation of the Carers Strategies (Wales) Measure is maintained once the Bill’s provisions come into force in 2016.

4.17 The Welsh Government made funding available to the local health boards and NHS trusts to support development of the Carers Information and Consultation Strategies during 2012-13. Further funding of £1.095 million is being made available to support implementation in each of the three years 2013-14 to 2015-16. These allocations contain a specific component to support implementation of the young carers chapters of these strategies.

Key actions:

The Welsh Government will:

- continue to implement the Carers Strategies (Wales) Measure 2010, and work with carers and other stakeholders to monitor and evaluate the outcomes it achieves for carers of all ages
- make funding available to local health boards and NHS trusts in 2013-14, 2014-15 and 2015-16 to implement the Carers Information and Consultation Strategies.
Chapter 5

Young carers and young adult carers

5.1 Young carers are children and young people under the age of 18 who provide care, support or assistance to a family member with care needs. The majority of young carers care for a parent, but the person with care needs may be a sibling, grandparent or any other family member. Young carers were identified as a key priority within the Carers Strategy for Wales 2000 and the 2007 Action Plan.

5.2 In the refreshed Carers Strategy we have decided to broaden our focus to include young adult carers aged 18-25. This recognises that, in addition to the transition issues to be considered as a young carer approaches adulthood between the ages of 16-18, there are also transition issues when a young person moves from being a young carer to being a young adult carer. The demographic of the carer population means that mainstream adult carer support services are not always best placed to meet the needs of young adult carers, and there is a need to ensure that appropriate support is in place for this specific group of carers. There are also particular issues to be considered around supporting young adult carers in accessing further or higher education, training and employment.

An integrated approach

5.3 The Welsh Government is committed to developing an integrated framework of support for carers of all ages. Rather than producing a separate young carers strategy, we have sought to integrate young carers and young adult carers fully into this Carers Strategy for Wales.

5.4 Many of the issues affecting young carers and young adult carers are common to all carers. We believe that having one integrated strategy will help agencies address these issues in the round, so that carers can benefit from joined-up services and support. It should also help break down barriers, particularly around key transition points (for example, from young carer to young adult carer to adult carer), both for the carer and the cared for person. An integrated approach is also consistent with the ‘people’ model we are developing through the Social Services and Well-being (Wales) Bill.

5.5 However, there are issues and considerations specific to young carers which need to be clearly identified throughout this strategy, and which require a specific focus and specific actions. These specific considerations stem from the fact that young carers are rights bearers under the United Nations Convention on the Rights of the Child. Above all, they have a right to enjoy their childhood. Issues specific to young carers include the vital role of schools and colleges in identifying and supporting them, and the particular barriers that children and young people often experience in accessing services and information. This is why we have identified young carers and young adult carers as a key priority area, and why there is a specific chapter on young carers and young adult carers in this strategy.
5.6 The guidance to local health boards, NHS trusts and local authorities on their Carers Information and Consultation Strategies requires them to adopt a similar approach. These local strategies cover carers of all ages, but also contain a chapter that focuses specifically on young carers. The Welsh Government has allocated specific funding to support the implementation of these chapters.

Listening to young carers

5.7 Article 12 of the United Nations Convention on the Rights of the Child gives children and young people the right to say what they think should happen when adults are making decisions that affect them, and to have their opinions taken into account. Since 2008 the Welsh Government has supported the Young Carers Network, facilitated by Children in Wales, to help young carers exercise this right. The Network brings together young carer representatives from each of the young carers projects across Wales. These regional meetings provide opportunities for mutual support, and a forum for young carers to discuss issues of mutual concern. Once a year a group of young carers from the Network meet with Welsh Ministers to present to the Welsh Government the experiences and views of young carers in Wales.

5.8 In 2012, the Network produced a Young Carers Film which set out young carers’ views in areas such as education, health, social services, identity and travel. Copies of this DVD were sent to each of the local health boards and to local authorities to assist them in preparing the young carers chapter of their Carers Information and Consultation Strategies. It has also helped to shape this strategy. The film may be viewed by following the attached link:
http://www.childreninwales.org.uk/areasofwork/youngcarers/dvdandleaflet/index.html

5.9 The Children’s Commissioner for Wales also takes an active interest in young carers. His report, ‘Full of Care’ (2009), made a series of recommendations to the Welsh Government, local authorities and the NHS, to improve the lives of young carers and ‘inject an element of urgency into reviewing how young carers are valued and supported in Wales’. The recommendations covered recognition; stress and its effects; increased opportunities for enjoying childhood; and medical matters. It also underlined the importance of early identification and intervention. The findings and recommendations in ‘Full of Care’ deal with similar issues to those raised by the Young Carers Network.

What young carers have told us

5.10 The young carers identified concerns in seven key areas: identity; the role of the Welsh Government and local government in supporting young carers; health; social services; education; transport; and social and leisure activities. The concerns are summarised in the box below.
Young Carers’ Views

Identity
There needs to be greater awareness of young carers, and a recognition that all young carers are different and that caring affects each young carer in different ways. Adults need to remember that young carers are still children or young people.

Government
The Welsh Government should write a young carers strategy. Every local authority should look at the support available to young carers. The Welsh Government and local authorities should fund services to support young carers and young adult carers up to age 25. Young carers need to have a say on local services, and all agencies should listen and respond to young carers’ concerns.

Education
Teachers need to be aware of the role of young carers, and make a positive difference when this affects punctuality, attendance or homework. There should be training and funding to support this, and general awareness raising among school staff and pupils. More needs to be done to help and support young carers and young adult carers in colleges and universities as well as schools.

Health
All health professionals need information and training on how they can identify and engage with young carers. Young carers should be told what is wrong with the person they care for and how they are being treated. Information needs to be free of jargon. Young carers should be able to highlight the training they need, and there should be guidance on the appropriateness of tasks such as administering medicines, toileting and manual handling. Chemists need to realise that young carers sometimes need to pick up prescriptions for the person they care for.

Social services
All social services professionals need to listen to young carers, and have information and training on how they can support them. There needs to be more respite care so young carers can have a life outside of caring. Young carers need support throughout their caring role, not just at crisis points. There needs to be better communication between adult and children’s services, to improve support for young carers and the people they care for.

Travel
Young carers need better public transport, and be able to access free or cheaper transport.

Social
Young carers need social activities and leisure opportunities at times suited to them, and at a free or cheaper price.
5.11 Common themes across these areas are:

- the need for government and professionals in health, education and social services to recognise young carers and understand the role young carers play
- the need for greater awareness raising and training for professionals so that they can identify, listen to and engage appropriately with young carers
- the need for adequately funded young carers services across Wales, and better support for young carers to access other services such as transport and leisure
- the need for ongoing support to young carers, not just when things go wrong.

5.12 There was also a call for recognised young carers identity (ID) cards, which young carers could use to discreetly show that they are young carers and seek help if they need it. These might also be used to claim benefits such as subsidised transport and leisure facilities.

5.13 Young adult carers have raised similar concerns including: awareness raising, recognition and support within further and higher education, training or employment; transition planning from children’s to adult services; training and support to assist them with their caring responsibilities; and a desire to enjoy the social activities that other young people take for granted.

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**Voices of Young Adult Carers: Stories of young adult carers’ experiences of caring and learning**

During Carers Week 2012, NIACE (National Institute of Adult Continuing Education, England the Wales) published a report containing the stories of eight young adult carers. ‘Voices of young adult carers’ gives a personal account of each of the young adult carers (aged between 16 and 25), focusing on their caring role and the impact that caring has had on their lives and particularly on their ability to take part in learning. All of the stories have been written by the individual carers in their own words.

Each of the eight stories gives an honest and realistic account of what life is like as a young adult carer. It is hoped that these stories will not only give hope and support to other young adult carers, but will also encourage providers and policy-makers to help all carers gain access to the learning they both want and need.

The report may be downloaded free from: http://www.niace.org.uk/news/voices-of-young-adult-carers
Responding to young carers issues

Recognition

5.14 The main vehicle for increasing awareness of young carers within health and social services are the local Carers Information and Consultation Strategies. The young carers chapters within these set out the steps local health boards, NHS trusts and local authorities will take to train and develop their staff in identifying, engaging with and supporting young carers. They also set out how age appropriate information and training will be provided to young carers, and how young carers and young adult carers will be consulted and involved in all decisions that affect them. GPs, social workers, and other health and social care professionals should all be included in the strategies.

5.15 Although education was not specifically included in the list of ‘designated authorities’ under the Carers Strategies (Wales) Measure, we would expect local authorities to consider the need to raise awareness of young carers within schools and colleges as part of their local authority carers strategies, linking as appropriate to the Carers Information and Consultation Strategies. Schools and colleges have a clear responsibility to consider the impact of caring upon the right of young carers to education (Articles 28 and 29 of the UNCRC).

5.16 To assist with awareness raising, the Welsh Government has launched a new on-line toolkit for professionals in health, education and social services. This fulfils a commitment given in the 2007 Carers Strategy Action Plan. It was developed by Youth Friendly with help from the Young Carers Network and other carers and professionals, to ensure that it gets across the messages young carers want. It updates the ‘Caring for Carers’ training resource for schools, which was issued in 2004, and it has been expanded to include young adult carers in further and higher education. The toolkit puts particular emphasis on identifying young carers and young adult carers, and how to engage with them appropriately to ensure that their needs are met. The toolkit will be disseminated widely to schools, colleges, young carers projects, and health and social services agencies. It will be regularly updated to ensure that it stays topical, and we would welcome any feedback.

5.17 The toolkit may be found at: http://youngcarerstoolkit.co.uk/

Pharmacists

5.18 The Young Carers Network raised a specific concern around the need for pharmacists to recognise and engage appropriately with young carers who may need to collect medicines on behalf of the person they care for. Young carers obviously want to be able to pick up prescriptions easily; but pharmacists also need to consider safeguarding issues around dispensing medicines to children and young people. The Royal College of Pharmacists has issued guidelines to its members on children and young people collecting prescriptions, which deals with these issues. The Welsh Government’s Chief Pharmaceutical Officer is seeking permission from the Royal College to disseminate the guidelines more widely in Wales, and will be writing to all pharmacists in the summer 2013 to draw their attention to the guidelines, particularly in relation to young carers. Public Health Wales is also
working with the Young Carers Network on case studies which can be used to raise awareness of these issues.

**Young carers services**

5.19. All local authorities in Wales have dedicated provision for young carers. Most have a young carers service run under contract with an external provider, usually from the third sector. Some local authorities are currently exploring other models – for example, in one authority young carers are assessed by a dedicated part-time social worker for young carers, who then refers and supports the young carer to access support from mainstream services. The Welsh Government will ask Directors of Social Services to provide information about the models currently in use across Wales, and the scope for evaluating different approaches.

**Identity (ID) cards**

5.20 Identity cards for young carers have been explored or piloted in a number of local authority areas in Wales. An example is the Access to Action (A2A) card which has been developed by Flintshire County Council and Barnardo’s Cymru. There has not yet been a co-ordinated attempt to gather information about these schemes or evaluate the effectiveness of different approaches; and there are as yet no guidelines for local authorities to use when setting up schemes.

5.21 The ID cards are primarily a way of getting young carers recognised, and an aid to dealing confidently with adults in schools, colleges, and health and social care settings. The box below outlines the A2A scheme, and gives examples of how the card might be used.

5.22 ID cards may also be used as proof of entitlement to subsidised transport or leisure facilities, or other services or support. The Welsh Government believes that ID cards are best developed at the local level in partnership with local young carers and other local agencies, especially as the extent to which the ID card is used to access subsidised local services is a matter for local determination.

5.23 To assist local authorities develop local ID card schemes, the Welsh Government will commission a study of existing pilot schemes, including different approaches, how they have been evaluated, and what lessons have been learnt. We will then work with the Young Carers Network and other partners (including local government) on a set of guidelines for those who wish to set up such schemes.

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**Access to Action (A2A) Card**

The Access to Action (A2A) card is a new ID card to help children and young people in Flintshire who are young carers, looked after children or care leavers. It was launched in June 2012, and is a collaborative initiative between Barnardo’s Cymru and Flintshire County Council.
These groups of young people often find it difficult to explain their circumstances in situations such as school, college, council services, GP surgeries, and other health services. The intention is that the A2A card will enable them to receive recognition of status, and prompt access to services, without having to explain their personal situation several times to different adults.

Examples of when it may be used include:

- to present if the young carer has been unable to complete homework, or is very tired at school due to the person they care for having been ill, or in need of a lot of their support the previous day or night
- to present at the social services reception desk when wishing to gain access to their social worker, in order to avoid having to explain any personal details in a public environment
- to present at pharmacies when picking up prescriptions for the person being cared for
- to present in the event of having to explain why they are unable to respond to unplanned events, such as an after school detention, due to specific transport arrangements they are committed to, care of other siblings after school, or due to the responsibilities of their caring role
- to present in order to support a request for, and access to, special arrangements, such as time in the school day to make a telephone call to the cared for person to make sure they are ok, or time out to attend meetings and/or appointments.

The idea for the A2A card came from the young people themselves. Young people from the Flintshire Young Carers, Looked after Children and Care Leavers Forums came together to work on the idea of the ID card, and were involved in coming up with the name, design and developing promotional material.

Promotion of the card is being taken forward in three phases:

- Phase 1 – roll out in Social Services and Education;
- Phase 2 – roll out in Health and North Wales Police; and
- Phase 3 – wider roll out hopefully including leisure, transport and retail services.
Key actions

The Welsh Government will:

- ensure that young carers and young adult carers are fully integrated into all Welsh Government policies and strategies affecting carers
- use the Social Services and Well-being (Wales) Bill to ensure that young carers can exercise their Convention Rights in respect of social and well-being services
- work with stakeholders to monitor and evaluate the outcomes achieved for young carers through the Carers Information and Consultation Strategies
- commission a study on young carer ID cards and produce guidelines for local authorities who wish to set up schemes
- continue to disseminate and promote the Young Carers Toolkit, and ensure that it is kept up-to-date
- promote the guidelines to pharmacists on young carers collecting prescriptions, and advise young carers to use, wherever possible, the same community pharmacy of their choice
- continue to support and fund the Young Carers Network and report back annually on our progress in addressing their concerns
- ask Directors of Social Services to provide information about the models for young carers services currently in use across Wales, and the scope for evaluating different approaches.
Chapter 6

Support and a life outside of the caring role

6.1 No carer can be expected to care 24/7 for 365 days a year. All carers must have reasonable breaks from their caring role. These breaks enable them both to maintain their capacity to care, and to have a life beyond caring. Carers will have different needs, expectations and preferences which will need to be taken into account when determining a reasonable pattern of caring. There also need to be contingency plans in place for when a carer is unavailable to provide care.

6.2 This chapter deals with how we can ensure that carers get the breaks they need from caring, and can pursue lifelong learning, recreational and leisure opportunities. Carers and employment is dealt with in Chapter 7.

6.3 Welsh Government guidance to local health boards, NHS trusts and local authorities on the Carers Strategies (Wales) Measure 2010 stated:

‘It must never be assumed that carers can or will provide care. Carers can choose whether or not they will care and the level of support they are prepared to offer. The amount of caring they can and are willing to do must be negotiated and regularly reviewed.’

6.4 This remains the Welsh Government's policy intention.

From ‘respite’ to alternative care

6.5 During 2010 the Welsh Government commissioned the first comprehensive research into respite services in Wales. Until this research was completed, limited evidence existed regarding the existing usage, capacity and range of respite provision across Wales, and the patterns and volume of demand for respite services. The research was undertaken by LE Wales and the final report (‘Respite Care in Wales’) was issued for public consultation in spring 2011. The report’s recommendations and the results of the consultation have been used to inform the development of this Strategy and have also fed into the development of the Social Services and Well-being (Wales) Bill.

6.6 For the purposes of the research, ‘respite care’ was taken to mean any services that enable carers to have a break from caring. The research highlighted some of the contradictions in popular and professional understanding of what ‘respite care’ was. Respite is popularly understood as being for the benefit of the carer – giving a carer a break from caring; but respite services are usually services for the cared for person. The research and consultation also revealed just how varied these ‘respite’ services can be. They include temporary placements in residential or nursing homes or in hospital, sitting services, day care provision, or assistance with a holiday either for the carer or the cared for person or both. Many innovative and flexible approaches are being developed across Wales, and consultation has shown that people want to retain this flexibility. The emphasis has to be on finding solutions and approaches which meet individual need and the preferences of carers and those they care for.
6.7 Rather than trying to develop a common ‘catch all’ definition or description of respite care services in this strategy, we have decided instead to focus on defining the outcomes we wish to achieve for carers. The Advisory Group recommended that we drop the elastic term ‘respite care’ and instead refer to ‘alternative care’ or ‘replacement care’. There was broad support for this among the responses to consultation on this strategy. In developing and implementing the provisions in the Social Services and Well-being (Wales) Bill, we will seek to develop a shared understanding of what ‘alternative care’ is and how it can be used to achieve positive outcomes for carers and those they care for.

6.8 There is general agreement that carers should get regular breaks from caring so that:

- they build resilience and are able to continue caring
- they can have a life beyond caring, including time to enjoy recreational and leisure activities, and (if they wish to) to pursue formal or informal learning opportunities
- they can maintain their own physical, mental and emotional health
- a more constructive partnership is built up between the carer, the person cared for and other agencies involved in that person’s care.

6.9 The Advisory Group also made the following suggestions for developing an approach to alternative care within the context of the Social Services and Well-being (Wales) Bill:

- Assessments of those who are cared for should be ‘carer neutral’. They should focus first on the needs of the people who are cared for, and the outcomes they wish to achieve; and only then should decisions be taken on how these needs might be met and the outcomes achieved, including how much care any carer is able and willing to undertake.
- Consideration should be given to costing care plans without taking into account the contribution made by any carer (factoring in the ‘uncosted’ cost). This should help local authorities reach a more realistic assessment of the likely cost of any alternative or emergency care, as well as helping to build a more general picture of the real cost of unpaid care.
- Assessments should be negotiated partnership assessments, and alternative care options for when the carer is not available should be specified in the care plan (and not be confined to contingency and emergency arrangements).
- Contingency plans, covering both formal and unpaid care should be shared with the cared for person and their family.

6.10 We will take these into account when developing the new integrated assessment and care and support process under the Bill and set out our
requirements in the Code of Practice that will be published under the provisions that it contains.

Recreational, leisure and lifelong learning opportunities

6.11 Recreational and leisure activities not only give carers a break from caring, but also help promote their overall health and emotional wellbeing. Many carers also value lifelong learning opportunities, to pursue a hobby or interest, or to help them retain or improve their employability. The cost of caring, including reduced earnings as a result of having to work reduced hours or give up work altogether, can impact on carers’ ability to take up these opportunities. We know that some local authorities already offer concessions to carers – for example, using eligibility for the Carer’s Allowance as a passport to concessionary lifelong learning opportunities, or providing them with a leisure card – but this is not consistent across Wales.

6.12 In taking this forward, we will:

- seek views on what recreational activities carers would most value, and gather evidence of what really makes a difference
- gather evidence and best practice where local authorities already have good links between social services and leisure services
- ensure that carers are written into health promotion and leisure initiatives, and strategies/action plans such as ‘Creating an Active Wales’.

Open University in Wales: Access to Education for Carers Project

Funded by the Waterloo Foundation, this project seeks to engage with carers of all ages in learning opportunities, to raise the aspirations and opportunities for carers to study in Higher Education so that they can enhance their knowledge, skills and confidence.

The Open University’s flexible distance learning methods are ideally suited to carers, who often have to study at unconventional times to fit in with their caring roles. The project:

- developed information specifically aimed at carers
- worked with carers groups to complement their informal learning programme, and provide enhanced support through taster sessions and face-to-face study clubs
- ran a bursary programme to help towards the cost of course fees for carers who are eligible for other financial support
- helped to influence the way the Open University responds to and supports its students who are carers.
As a result carers have become one of the widening access priority groups for the Open University across the UK, and the University is now working on developing a carers ‘flag’ to highlight students who are carers.

Further information may be found at: www.openuniversity.co.uk/carersproject

The Open University has also produced a booklet called ‘Studying while you care: A brief guide to ways The Open University can help support students who have caring responsibilities’.

Welfare reform

6.13 In addition to NHS services and local authority social services, many carers also receive support from the State through the welfare benefits (or social security) system. This can come either directly through the Carer’s Allowance, the Carer Premium, or the Carer Addition to Pension Credit; or indirectly through benefits paid to the cared for person and which contribute to the overall household income. Unlike the NHS and social services, the welfare benefits system is non-devolved, and responsibility rests with the UK Government through its Department for Work and Pensions. In 2010 the UK Coalition Government embarked upon a series of substantial changes to the benefits system, under its ‘Welfare Reform’ programme.

6.14 The impact of these changes upon carers in Wales is difficult to predict and will only become known over time. At present the UK Government has announced no changes to the Carer’s Allowance or to the Carer Addition to Pension Credit, and carers currently in receipt of means-tested benefits such as Income Support and Jobseekers Allowance with a carer premium will continue to receive an additional amount for caring once these benefits have been replaced by Universal Credit. In the longer term, however, the UK Government is committed to reviewing the operation of carer benefits in the light of the introduction of Universal Credit. In the shorter term, some carers are likely to be affected by the replacement of Disability Living Allowance (DLA) by a new Personal Independence Payment (PIP) from April 2013, as DLA acts as a ‘passport’ to the Carer’s Allowance (if the person cared for receives the middle or higher rate care component of DLA). Although the UK Government has confirmed that both rates of PIP will act as a passport to the Carer’s Allowance, modelling suggests that by 2015 there will be a reduction of over 20% in the number of people eligible for PIP compared with those who would have been eligible for DLA. It is not known how many carers will lose their eligibility for the Carer’s Allowance as a result.

6.15 Welsh Ministers have expressed grave concerns about the pace and scale of the UK Government’s Welfare Reform agenda, and its likely impact upon Wales, and have made representations to the UK Government on these issues, including the potential consequences for carers. A Ministerial Group has been set up to co-ordinate the Welsh Government’s response to these changes, to monitor their impact upon people in Wales, and to find ways of mitigating the negative impact of the changes within the limits of the Welsh Government’s devolved powers. The Welsh
Government will continue to assess the impact of Welfare Reform and consider what mitigating action can be taken.

**Key actions:**

The Welsh Government will:

- develop a shared understanding of alternative care, and how it can be used to achieve positive outcomes for carers and those they care for, in the context of the Social Services and Well-being (Wales) Bill
- consider how best to promote greater access for carers to recreational and leisure opportunities to promote their health and well-being
- continue to monitor the impact of the UK Government’s Welfare Reform programme on carers in Wales, and, wherever possible, strive to mitigate any negative effects on carers and those they care for.
Chapter 7

Carers and employment

7.1. Carers who work, or wish to access work, should be enabled to do so. This chapter focuses on helping carers retain employment, helping carers to move into employment, and encouraging carers to think about employment and increasing their employability.

7.2. The key to carers retaining or accessing employment is flexibility, and a priority within this chapter will be to promote flexible approaches which meet the needs of employers and of those employees who are carers.

7.3. Many issues around employment are non-devolved and remain the responsibility of the UK Government. The Welsh Government is, however, a leading public sector employer with direct responsibility for the NHS workforce, and its policies impact upon local authority and other public sector workforces. It also has responsibilities in relation to business, enterprise, and skills-based learning.

7.4. Carers UK commissioned a major report, ‘Who Cares Wins: The Social and Business Benefits of Supporting Working Carers’ (2006), which showed that by using a flexible working approach, employers can provide effective support for carers at work and achieve significant business benefits. It also contained examples of good practice which all employers could adopt. The report may be downloaded at: http://www.carersuk.org/professionals/resources/research-library/item/509-who-cares-wins-the-social-and-business-benefits-of-supporting-working-carers

7.5. The economic context has, however, changed considerably since then. Then the emphasis was on retaining staff and their skills and experience. Now there are fewer job opportunities and the employment market is insecure. We need to make the case for supporting carers in employment in a new way to meet the challenges of the workplace in challenging economic times, and be creative in the levers we pull. This should not mean retreating from previous standards of good practice – with increasing numbers of the working age population balancing paid employment with caring responsibilities, the moral and business case for supporting working carers remains as strong as ever. Adopting a flexible approach to supporting employees with family and caring responsibilities can bring both increased productivity and employee commitment. That is why we wish to use this refreshed Strategy to re-emphasise and promote good practice. Key partners in this will be Jobcentre Plus, the Confederation of British Industry (Wales), local chambers of commerce, work-based learning providers, and further education colleges.

The Coleman case

Sharon Coleman was a legal secretary who sued her former employers, claiming that she had been discriminated against because of her disabled son. This included making it difficult for her to take time off to look after her son. The case was unusual because Ms Coleman was claiming discrimination by association with a person from a legally protected group (a disabled person).
The case was sent to the European Court of Justice to determine whether discrimination by association was prohibited under European law. In July 2008 the European Court of Justice ruled that it was. An Employment Tribunal subsequently confirmed that this applied to the UK’s disability discrimination laws also. The Equality Act 2010 clarified this issue, and extended it to cover goods and services.

7.6. The legal framework for supporting carers in the workplace includes provisions in the Work and Families Act 2006, which came into force in Wales in April 2007. The Act widens the scope of the existing law on flexible working to enable more people with caring responsibilities to request to work flexibly. A ruling by the European Court of Justice in 2008 in the ‘Coleman’ case also helped to extend legal protection in the workplace to carers and others associated with protected groups. This was extended by the Equality Act 2010. The Welsh Government’s Strategic Equality Plan also has a focus on addressing pay and employment differences, particularly in relation to gender, ethnicity and disability, which may also be of benefit to carers. For example, as women are more likely to take on a caring role than men, providing affordable and accessible childcare and flexible working can particularly help female carers who are in employment.

7.7. The Welsh Government’s Department for Economy, Science and Transport promotes the benefits of corporate social responsibility to Wales’ businesses and is committed to working with enterprises to build healthy, safe and fair workplaces. This include encouraging businesses to support carers in the workplace.

7.8. There are various award schemes for employers who are committed to supporting carers in the workplace. These include the Carer Friendly Employer Recognition award which has been developed by various partner agencies in North Wales, and the Small Workplace Health Award which is delivered by Public Health Wales for the Welsh Government. We will use this Strategy to promote these award schemes and encourage employers to work towards them.

7.9. The Welsh Government values diversity among its own employees, and aims to create an inclusive workplace where equality and diversity are valued and seen as key to successfully delivering high-quality services to the people of Wales. Its Carers Policy aims to support employees to remain in work, fulfil their career potential and meet their caring responsibilities. It provides a wide range of flexible working options (part-time working, term time working, job share, compressed hours and homeworking) and Special Leave (paid and unpaid) which carers can use to help balance their work with their caring responsibilities. Carers who have a significant caring responsibility and need more than three months away from their work can apply for a career break of up to five years.

**Carer Friendly Employer Recognition Award**

Piloted among employers in North East Wales in 2011, this award is based around a set of simple standards which employers can adopt to support carers in the workplace. The emphasis is on the small changes that
employers can adopt, at little or no cost, to support their employees who are carers, and also the benefits that this can bring to the employing organisation. The award was developed by Glyndwr University in partnership with Carers Trust, North East Wales Carers Information Service (NEWCIS) and Wrexham Carers.

Benefits include retaining the investment made in employees and improved performance associated with increased loyalty and flexible working options. The standards also help employers to fulfil their legal obligations towards carers under the equality legislation.

The standards are designed to be flexible, and the way they are implemented will depend on the size, operational framework and nature of the organisation. The standards are based on the following steps:

- the employer identifies carers in the organisation
- the employer adopts a carer friendly infrastructure
- the employer commits to equitable provision for carers
- an opportunity is provided to hear the voice of carers in the workplace
- where reasonable and practicable, the employer allows flexible working practices.

Small Workplace Health Award

The Small Workplace Health Award has three levels of award (Bronze, Silver and Gold) to recognise each development stage achieved. It consists of core components and healthy lifestyles topics for each level.

The award is delivered for the Welsh Government by Public Health Wales, with employers supported by a Workplace Health Advisor for Public Health. The service is free of charge to all employers in Wales, given the Welsh Government's funding. We would advocate the award to all employers in Wales, as it also provides a framework for employers to follow to maintain and improve the health and well-being of their staff. The employers pack may be downloaded via the following link:

http://new.wales.gov.uk/topics/health/improvement/index/smallworkplace/?lang=en

The award is complemented by the Corporate Health Standard for larger workplaces with more than 50 employees.
Key actions

The Welsh Government will:

- capture the learning from existing projects on carers and employment in Wales, and disseminate and promote good practice
- promote the adoption of awards for employers who support carers in the workplace, including the Carer Friendly Employer Recognition Award and the Small Workplace Health Award.
Summary of Key Actions

Health and Social Care

- We will legislate for enhanced rights for carers through the Social Services and Well-being (Wales) Bill.
- We will work with carers to develop a new national eligibility framework supported by an integrated assessment process.
- We will promote recognised toolkits that promote improved standards for carer support within GP practices.
- Ensure that carers continue to be included in health, social care and other relevant policies and strategies such as ‘Together for Mental Health’ and ‘Working Together to Reduce Harm’.

Identification, information and consultation

- We will continue to implement the Carers Strategies (Wales) Measure 2010, and work with carers and other stakeholders to monitor and evaluate the outcomes it achieves for carers of all ages.
- We will make funding available to Local Health Boards and NHS Trusts in 2013-14, 2014-15 and 2015-16 to implement the Carers Information and Consultation Strategies.

Young carers and young adult carers

- We will ensure that young carers and young adult carers are fully integrated into all Welsh Government policies and strategies affecting carers.
- We will work with stakeholders to monitor and evaluate the outcomes achieved for young carers through the Carers Information and Consultation Strategies.
- We will commission a study on young carer ID cards and produce guidelines for local authorities who wish to set up schemes.
- We will continue to disseminate and promote the Young Carers Toolkit, and ensure that it is kept up-to-date.
- We will promote the guidelines to pharmacists on young carers collecting prescriptions, and advise young carers to use, wherever possible, the same community pharmacy of their choice.
- We will continue to support and fund the Young Carers Network and report back annually on our progress in addressing their concerns.
- We will ask Directors of Social Services to provide information about the models for young carers services currently in use across Wales, and the scope for evaluating different approaches.
Support and a life outside of the caring role

- We will develop a shared understanding of alternative care, and how it can be used to achieve positive outcomes for carers and those they care for, in the context of the Social Services and Well-being (Wales) Bill.
- We will consider how best to promote greater access for carers to recreational and leisure opportunities to promote their health and well-being.
- We will continue to monitor the impact of the UK Government’s Welfare Reform programme on carers in Wales, and, wherever possible, strive to mitigate any negative effects on carers and those they care for.

Carers and employment

- We will capture the learning from existing projects on carers and employment in Wales, and disseminate and promote good practice.
- We will promote the adoption of awards for employers who support carers in the workplace, including the Carer Friendly Employer Recognition Award and the Small Workplace Health Award.
Endnotes


5 ‘Carers Strategies (Wales) Measure 2010 – Guidance issued to Local Health Boards, NHS Trusts and Local Authorities’ (December 2011)