

Warwickshire Joint Carers' Strategy Refresh Summary

Carers are everybody's business

2012 - 2015





Forward

Carers make a significant contribution to the lives of the people that they care for and to society as a whole.

What our carers say:

"I support him with the day to day things."

"I just felt as if I was taking everything on my shoulders."

"There are loads of aspects of help you can get but at the time you don't know that it's there."

"It felt like someone had thrown a life jacket and I wasn't sinking anymore"

With as many as three in five people becoming a carer at some point in their lives, most of us will either be a carer or know a relative, friend, colleague or neighbour with caring responsibilities.

The growing ageing population and increased number of young people with complex disabilities mean that carers will be even more at the forefront of our communities in the future providing vital, unpaid care at a time when health and social care budgets are under pressure.

Yet while we acknowledge the vital support carers are providing in our society we have to ask, how is society supporting carers?

Through our on-going work with carers we have found that too often carers are losing out in terms of their relationships, health, education and employment opportunities or they are unaware of the help available and struggle to get the right support at the right time. This clearly has to change.

Through the Warwickshire Carers Strategy we are committed to ensuring that carers are recognised, valued and supported. We have produced the strategy in partnership with carers and the people they care for, NHS Warwickshire, and carers' support services to respond to the key issues.

We recognise carers will only receive the right support if they are adequately informed about the options open to them. That is why we aim to identify carers as early as possible so they can access the information and advice they need to make informed choices about their lives. We believe that carers have the right to fulfil their educational and employment potential. This strategy places a strong emphasis on working with children's services so that young carers are able to achieve and access the same opportunities as other young people, as well as receiving support that is based around a whole family approach. We are working with carers so they can access training opportunities and employers to promote new, modern ways of supporting staff with caring responsibilities.

We understand the circumstances of each carer will be unique, and that is why there is an overriding need to personalise support to fit around an individual so they can have a family and community life.

We also know that carers often sacrifice their own physical and mental health to look after someone else. We are working with GPs to provide regular health checks and through our work with carers' support services we are ensuring carers are able to access emotional support.





The Warwickshire Carers Strategy includes a comprehensive delivery plan which will be implemented over the next two years. By improving information for carers about the emerging services which will help them and the people they care for, carers will be able to make better informed choices to meet their needs within their communities.

We want to help adults and children who live and care in Warwickshire to improve their quality of life, health and wellbeing. By working together, including with businesses and the community, we can make a difference for the better.



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Cllr Izzi Seccombe Portfolio Holder for Adult Social Care

To find out more from carers in their own words and for other information and advice please log on to www.warwickshire.gov.uk/carers





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Section One

1.1 Introduction

Health and social care services are dependent upon the role played by informal carers. The most recent estimate of the saving to the NHS through the care provided by informal carers is £119 billion¹ nationally, the equivalent of funding the whole NHS. In the current economic climate this support is more valuable than ever and yet many carers find themselves without adequate support or even access to information that could make their role easier to sustain. Research² has clearly identified a link between caring and deteriorating health and the negative impact this is having on those members of our communities who are providing this care, including a significant proportion of children and young people.³ Considered in purely economic terms we are failing to invest in one of our most valuable resources. In human terms we are allowing some of our citizens, their children, and the people they care for to live unnecessarily difficult lives with long term consequences for carers' health, and economic opportunities.

This strategy has been developed as a framework for a more holistic approach to supporting carers which builds on, and contributes to, key developments related to carers within other strategies and the re-organisation of health services. It provides a clear guide to the commissioning of services that will support and enable carers to continue in their caring responsibilities and participate in family and community life

1.2 Who are carers?

A carer is someone of any age who provides unpaid support to family or friends who could not manage without this help. This could be caring for a relative, partner, a child or friend who is ill, frail, disabled or has mental health or substance misuse problems. 4

Young carers are children and young people (up to the age of 18) whose life is affected by looking after someone with a disability or long-term illness. The person they care for may be a parent, a sibling, another family member or a friend. The terms 'disability' and 'long term illness' do not just mean a physical illness or disability, but also cover, for example, mental illness, learning disability, substance misuse, frailty and old age. Many young carers continue to become Young Adult Carers (aged 16-25).

Anyone can become a carer; carers come from all walks of life, all cultures and can be of any age. Many feel they are doing what anyone else would in the same situation; looking after their parent, partner, child or best friend and just getting on with it. A caring role may last a few months or years but for some it may last for the rest of their lives.

⁴ Recognised, valued and supported: Next steps for the Carers Strategy, 2010





¹ Carers UK, 2011

² Always on Call, Always Concerned, Princess Royal trust for Carers, 2011

³ Becker, Aldridge and Dearden, 1998

1.3 Policy Framework

The National Strategy for Carers, Carers at the heart of 21st century families and communities: A caring system on your side. (June 2008) has five key objectives stating that carers should be:

- Respected as expert partners in care and will have access to the integrated and personalised services they need to support them in their caring role
- Able to have a life of their own alongside their caring role
- Supported so that they are not forced info financial hardship by their caring role
- Supported to stay mentally and physically well and treated with dignity; and that,
- Children and young people need to learn, develop and thrive, to enjoy positive childhoods and to achieve positive educational and social outcomes, while being protected from inappropriate levels of caring.

The National Strategy sets out the government's commitment to services for all carers including those under eighteen and acknowledges the current difficulties many carers experience in accessing services from health and social care.

The National Strategy was updated by the Coalition Government in *Recognised, valued and supported: Next steps for the carers strategy (2010)* which includes more direction as to the priorities for action. The update to the carers' strategy highlights the importance of carers having control over the support and services they receive and re-states the target of everyone who is eligible for personal budgets, and wishing to take them up, having one by April 2013. This is a target that Warwickshire County Council has also adopted.

Warwickshire County Council and its partners are committed in their determination to address the gaps that exist in meeting the needs of young and adult carers. The achievement of this goal requires a strategic plan which, not only sets out the direction of travel, but defines the actions needed, the agencies responsible and includes measurable outcomes.

This Carers' Strategy Refresh builds on the previous Warwickshire Carers Strategy 2009 -2012 and takes account of developments in supporting young and adult carers and their families both nationally and locally.

The priorities are detailed in Section two of this document.

1.4 Legal Framework

The legal framework currently governing support for carers is poised on the threshold of significant and far reaching change. New legislation and policy directives are combining to raise the profile of carers by giving them new rights and requiring improved methods of identification with a view to providing them with support. The major changes for carers are contained in the following:

Caring for our future: Reforming care and support White paper 2012

This document contains proposals for transforming care and support in two major ways: by promoting people's wellbeing and independence through better information and earlier identification and intervention; and, giving people greater control and choice over the services they use.





It refers to carers throughout and identifies the underpinning principles as:

- The health, wellbeing, independence and rights of individuals are at the heart of care and support; timely and effective interventions help to ensure a good quality of life for longer.
- People are treated with dignity and respect, and are safe from abuse and neglect; everybody must work to make this happen.
- Personalisation is achieved when a person has real choice and control over the care and support they need to achieve their goals, to live a fulfilling life, and to be connected with society.
- The skills, resources and networks in every community are harnessed and strengthened to support people to live well, and to contribute to their communities where they can and wish to.
- Carers are recognised for their contribution to society as vital partners in care, and are supported to reach their full potential and lead the lives they want.
- A caring, skilled and valued workforce delivers quality care and support in partnership with individuals, families and communities.

The Government has committed to extending flexible working rights to all employees, thereby removing any stigma that may attach to requests for changes in working patterns. Skills for Care, the organisation with responsibility for developing the skills of the care workforce is working closely with employers through the Employers for Carers Forum to encourage better workplace support for carers.

The role that local authorities play in care and support is changing. Instead of purchasing or providing care and support, authorities will increasingly be expected to take a leadership role in a local area: identifying the needs of the local population, supporting communities to keep people active, empowering people to take control through personal budgets and direct payments, providing information and advice, and ensuring a responsive range of care and support options is available.

The Draft Care and Support Bill

The **Draft Care and Support Bill** places the promotion of individual well-being as the driving force behind care and support and aims to pull together previous social care legislation (including all the previous Carers legislation) into one unified act with a simplified approach and more consistent pathways. It also provides the legislative framework for recent policy developments such as personalisation. It is anticipated that the Bill will pass into legislation in 2013/14 and will be implemented in 2015.

The period covered by this Strategy runs parallel with the timetable for consultation and implementation of the Bill and provides an opportunity to plan with all stakeholders for the changes it may bring in business process, training of staff and sourcing and resourcing of possible new services. The Delivery Plan in Section 4 of this Strategy focuses on key areas for attention.





The elements of the draft Bill which have particular relevance to carers are as follows:

- A duty on Local Authorities to provide an information and advice service to help people
 understand how the care system works, what services are available locally and how they
 can be accessed. Local Authorities would also have a duty to ensure a diverse range of
 quality services to meet needs and to work with other local organisations to integrate
 services with the aim of promoting well-being and improving quality and outcomes.
- A duty on Local Authorities to take a proactive approach, make earlier interventions and provide services which are intended to prevent, delay or reduce people's needs for care and support. The aim will be to prevent or reduce dependency rather than responding to crisis situations.
- Carers will, for the first time, have a legal right to have a carer's assessment of their needs
 without having to meet the requirement that they are providing substantial and regular care.
 The duty on Local Authorities regarding carers will be comparable with that for the people
 they care for. There will be a new framework for assessing eligibility for support which will
 be set out in regulations.
- There will be a new duty on Local Authorities to meet carers' eligible needs and to review their care and support plan regularly to ensure that their needs continue to be met. Local authorities will be required to meet the eligible needs of carers by providing services to the cared for or to the carer. Services which might prove most helpful to carers could include help with housework or gardening, or the purchase of a laptop to help them stay in touch with family and friends, or gym membership to support the carer's own health and wellbeing. The draft Bill also allows for the carer's needs to be met by providing support directly to the person they care for through replacement care to enable the carer to take time away from the caring role.
- Carers will have new rights to be consulted in relation to the assessment and support plan of the person they care for and to have a copy of the support plan.
- Young carers under the age of 18 who care for adults will be supported by children's services rather than adult care and support. At the age of 18 the responsibility will switch to adults services although adult services can be brought into transitions planning before the young carer's 18th birthday at the carer's request. There will also be a new duty to continue any children's services which a young carer is receiving past the age of 18, if appropriate adult care and support is not in place.
- New provisions in the draft Bill will enable parent carers to be assessed under adult law as well as children's law enabling them to access services that they may currently be unable to use.
- Deferred payment options ie repayment of care charges from the sale of the customer's home are to be routinely offered with Local Authorities likely to be able to charge interest on the deferred payment.
- There will be a single, consistent route to establishing entitlement to care and support for adults. Eligibility will be determined by a national threshold rather than by individual local authorities.





Adult safeguarding will be strengthened by the creation of a clear framework of responsibilities and governance arrangements, including the establishment of a Safeguarding Adults Board to support a strategic and integrated multi-agency approach.

The Social Care (Local Sufficiency of Supply) and Identification of Carers Bill

This is a Private Member's Bill which has strong cross party support. It makes several key provisions which would help support the draft Care and Support Bill. If successful it would place duties on local authorities to:

- Provide sufficiency of supply of social care services
- Ensure sufficiency of supply of social care services for disabled people and carers who wish to work or go into education; and
- Require NHS and schools and further and higher education establishments to identify young carers

The duty to identify carers would be invaluable in raising the profile of carers' needs and could be a powerful tool in bringing carers into the mainstream and helping to ensure that carers really are everybody's business. The requirement to provide a sufficiency of supply recognises that carers and people with disabilities have the right to expect appropriate services to be available to support them in returning to or maintaining their employment in much the same way that local authorities have a role to play in ensuring appropriate provision of childcare to enable parents to work if they wish to.

The Power of Information – A ten year framework for transforming information for the NHS. public health and social care.

Published by the Department of Health this information strategy commits to a single integrated national website for health and care information. It will offer carers the ability to access services as well as health and care records online subject to authorisation by the person being cared for. It will be possible for carers to have access to information they need to help the person they care for through a single portal reducing the complexity of navigating web systems.

The framework calls for the offer of information prescriptions for people providing up-to-date. accurate information accessible directly online or via health professionals sourced from the NHS and patient organisations about specific conditions, treatment options, housing support, benefits, local care services, self-help and support groups.

NHS Care Objectives: Draft mandate to the NHS Commissioning Board.

The main areas of importance for carers within this mandate are to:

- Improve the quality and availability of information about NHS services, with the goal of having comprehensive, transparent, and integrated information and IT, to drive improved care and better healthcare outcomes. Alongside local authorities and the voluntary and community sector, the NHS has an important role in supporting carers both to care effectively and to look after their own health and wellbeing. To facilitate both new and experienced carers in accessing information, advice and support, including appropriate respite care.
- Improve the support that carers receive from the NHS, in particular by early identification of a greater proportion of carers, and signposting to information and sources of advice and support; and, working collaboratively with local authorities and carers' organisations to enable the provision of a range of support, including respite care. Working for Warnickshire





NHS Operating Framework 2011-13

This has clearly stated objectives in relation to carers and these can also be found in more detail in Appendix 2. In brief, these objectives require Primary Care Trusts and Local Authorities to work closely together to agree funding and support for carers in their localities. Appendix Three: Expenditure on Support for Carers includes the funding for these arrangements.

Clinical Commissioning Groups (CCG's)

From April 2013 Warwickshire will have three Clinical Commissioning Groups (CCG's): Warwickshire North CCG (covering North Warwickshire and Nuneaton and Bedworth), Coventry and Rugby CCG and South Warwickshire CCG. These groups will take on some of NHS Warwickshire's commissioning responsibilities as part of the Government's plans for the NHS and together with the NHS Commissioning Board will be responsible for working with local partners to ensure that carers are identified and supported. Public health will transfer to Warwickshire County Council.

Arden/Warwickshire Clinical Commissioning Groups (CCG's) fully appreciate the role, knowledge, expertise, value and contribution of all carers in Warwickshire and will recognise carers importance by continuing to fund a range of services to support their health needs and to provide respite care. CCG's will continue to work with partner organisations to identify carers and their personalised requirements, which fit with individual needs and family preferences.

At the time of drafting this Strategy South Warwickshire CCG has already clearly stated an expectation that its providers should "ensure that the ethos of 'No Decision About Me Without Me' is demonstrable in all services, and ...that patients and their families/carers be involved in developing care plans and development of services" and that the "views of local GP practices, patients and carers" will inform commissioning priorities.

The Coventry & Rugby CCG has also committed to working with "practices and staff to develop a culture of seeking the views and experiences of our patients and their families at every step, to help us further improve the quality of our local services".

The outcome frameworks for the CCGs are still being finalised at the time of writing this Strategy but it is the intention of Warwickshire County Council to establish robust working relationships with the CCGs and this Strategy's delivery plan underpins this aim.

Warwickshire North CCG shares similar expectations of its providers to SWCCG and their Commissioning Intentions equally reflect this.

Details of the relevant current legal framework governing support to carers can be found in Appendix 2 of this document.

1.4 How we developed this strategy

This strategy is based on the four key priorities within the National Carers Strategy⁵ and those identified by Warwickshire's own carers. To establish local priorities we have drawn on the draft

⁵ Recognised, valued and supported: Next steps for the Carers Strategy, 2010





Joint Health & Wellbeing Strategy, the Joint Strategic Needs Assessment, Warwickshire County Council's Corporate Business Plan 2012/13 and the outcomes of recent consultations carried out as part of the Learning Disability Strategy and Dementia Strategy work and also conducted a survey of carers, parents caring for a child with a disability and Young Carers in Warwickshire. Workshops with carers have enabled us to achieve a deeper understanding of key issues raised in the consultation. Carers who are part of the Transformation Assembly have also been involved in reviewing and refining the content of this Strategy document.

We have striven to ensure that carers who have been historically under represented among carers accessing support services, such as parents or carers of people with Autism, carers who have an illness or disability themselves, carers from some black and minority ethnic communities, carers who are trying to balance caring with work, carers supporting someone with a terminal diagnosis and carers who are providing care for someone who lives a long distance away are also included in this Strategy.

1.5 Financial Support for the Carers' Strategy Refresh

A detailed account of the financial support for this Strategy can be found in Appendix 4 of this document. The principles upon which this financial support is based are:

- Promotion of the use of universal services
- Replacement care services which enable carers to take a break are provided as part of an adult customer's support plan and charged to the customer
- For carers who meet Fair Access to Care (FACS) eligibility criteria support to enable them to live a life outside of their caring role will be provided via Direct Payments which are not currently subject to charging
- Carers are "everybody's business" carer awareness training is made freely available to frontline staff across Warwickshire County Council, Health and other partner organisations, improving identification of carers and appropriate signposting to support
- Carers assessments are "everybody's business" frontline members of operational social care teams for Physical Disabilities, Older People, Learning Disabilities and Mental Health are equipped to assess and support both customers and carers; within an acute setting, nurses' health assessments of patients involve and consult carers
- Joint planning with the Primary Care Trusts (in existence until March 2013) and Clinical Commissioning Groups wherever possible and appropriate.
- Subject to the recommendations relating to carers in the Draft Care and Support Bill passing into legislation further financial modelling may be required to address likely fiscal impact.

1.7 Monitoring of the Carers' Strategy Refresh

The detailed framework for monitoring and evaluating the achievement of this Strategy's priorities can be found in Appendix 5 - Making it happen and knowing when we have.

In brief, the monitoring approach incorporates statutory measures aligned to the Adult Social Care Outcomes Framework for 2012/13⁶, Warwickshire County Council's Corporate Business Plan 2012/13 and Strategic Delivery Framework, and the NHS Operating Framework requirements. Carers within the Transformation Assembly will be involved in evaluating progress and achievement

⁶ Transparency in outcomes: a framework for quality in adult social care



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Measures and outcomes relating to carers will be incorporated into all strategic documents and for all client groups and will be subject to the rigorous monitoring and evaluation processes adopted for assessing the achievement of individual strategies.

The key outcomes against which the success of this Strategy will be evaluated are those identified as priorities by carers themselves:

- Young Carers are able to thrive and achieve their educational goals
- Carers are able to access financial/benefits advice and information
- Carers are able to access practical information/ support for their caring role
- Carers are able to retain, or return to, employment
- Carers are able to have a family and community life
- Carers are able to take a break away from their caring role
- Carer have access to emotional support.

1.8 Glossary of Terms

You may come across the following terms in this document:

Customer - person using social care services

Direct Payment - payment made to a customer or carer's bank account following an agreed support plan for them to use flexibly to achieve their desired outcomes

Resource Allocation System - tool for allocating funding in relation to assessed needs.

Replacement Care - support provided to enable the carer to have time away from the caring role. This may be for a period of hours or days and may also be referred to as carers breaks or respite.

Memorandum of Understanding - A formal declaration by Adults' and Children's Social Care Services to work more closely together to ensure that young carers are better identified and supported





Section Two

2. Overall Vision for the Warwickshire Carers' Strategy Refresh

All carers, including those under eighteen, will be supported in their caring role to help maintain a balance between their caring responsibilities and their life outside of caring whilst supporting the person they care for to achieve their own outcomes.

This vision is founded on the following principles:

- Co-production we will work in partnership with carers to design, commission and develop services that support them
- Partnership we will work with other key stakeholders in health, social care and the independent and voluntary sectors
- Communities we aim to increase the capacity of communities to develop networks of support
- Personalised Support we will use a whole family approach in assessing for and delivering support to ensure that carers and cared for receive individualised and appropriate services that help them achieve their own outcomes. We aim to build upon what carers are able and willing to do and take into full account the appropriateness of their input and the impact of caring on them. This approach recognises that many adult carers are unable to draw on extended family support and that some customers may need services to reduce the impact of caring responsibilities
- A Life Outside Caring services provided will support the carer to have a life outside of caring and help to sustain the caring role
- The Right Service at the Right Time securing the right services, at the right time, in the right place, for the cared for, will reduce the need for carers to have services in their own right.
- Criteria for access to services criteria for access to non-universal services eg social care assessments, personal support, replacement care and reablement will be readily available and clearly stated.

2.1 Framework for the Carers Strategy Refresh

The Carers' Strategy published in 2008 identified five outcomes for carers to be achieved by 2018. These are that carers should be:

- Recognised and supported as an expert care partner
- Able to enjoy a life outside caring
- Not financially disadvantaged by their caring role
- Mentally and physically well and treated with dignity; and that,
- Children and young people will be thriving, protected from inappropriate caring roles.

The Coalition Government has refreshed this strategy, retaining these aims but identifying four priority areas which incorporate the above outcomes:

Priority 1 -Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.





Priority 2 - Enabling those with caring responsibilities to fulfil their educational and employment potential.

Priority 3 - Personalised support both for carers and those they support, enabling them to have a family and community life.

Priority 4 - Supporting carers to remain mentally and physically well.

This Strategy details how we will work within these priorities to deliver better outcomes for carers in Warwickshire.







Priority 1

Supporting early self-identification and involvement in local care planning and individual care support planning

Information

Although 3 in 5 of us are likely to help to look after someone during our lifetime caring is not something that most people expect to happen to them. Over 84% of carers surveyed recently did not anticipate ever having to carry out this role. In addition, people with caring responsibilities often do not identify themselves as carers and may even be distressed to be addressed as such. Research⁷ has shown that people may be providing care for several years before they consider themselves to have this role and this is particularly the case where the cared for is an ill or disabled child when the carer usually prefers to describe themselves as a parent.

Information is an early requirement when someone takes on caring responsibilities. Consultation⁸ and successive national and local surveys have cited this as key to enabling and sustaining a caring role. 37% of respondents to local consultation in Warwickshire⁹ indicated that they have experienced difficulty in accessing the information they needed and for some carers, such as parents and carers of those on the Autistic Spectrum, this figure was nearer 60%.

"Once I had my son's diagnosis we were left to source information for ourselves...I felt abandoned" Warwickshire Carer

The type of information most required by carers is information related to the illness/disability of the person they care for with practical guidance on how best to manage the care for that person, benefits/financial advice, and support for themselves in the form of a listening ear, support group or emotional support and a break. Carers in Warwickshire have expressed a preference for being able to access information at or near the point of diagnosis and for this to be offered in a variety of ways.

These local findings echo those being identified at a national level. In 2009 the Department of Health commissioned Carers Direct, a national, focused information and advice service for carers comprising an information website and a contact centre offering a telephone helpline. The aim of the combined service was to provide an easily accessible information and support service for carers which was able to signpost to local sources of support. A recent review of the service for found that significantly fewer people had accessed it than originally expected concluding that people may not identify themselves as carers and may not know what social care has to offer or where to look for this information. It also concluded that carers are not an homogenous group and their information requirements need to be met in a variety of ways with a web-based approach providing only part of the picture. Part of the reasoning behind these conclusions came from findings that 60% of adults 65+ have never accessed the internet and that adults in lower socioeconomic groups are less likely to access the internet.

The most popular reasons for people calling the Carers Direct Helpline related to welfare benefits for themselves, and those they care for, and social care assessments. The most frequent

¹⁰ Review of Carers Direct Information and Advice, Dept of Health, 2012





⁷ Carers UK, 2009

⁸ Carers Strategy Refresh Carers Questionnaire, WCC, 2012

⁹ Carers Questionnaire, WCC 2012

outcomes from calls involved being signposted to local authorities/organisations or other sources of specific information regarding benefits or assessments.

The draft Care and Support Bill published in July 2012 sees information as a priority and includes a requirement on local authorities to have robust and accessible information provision for local users of social care services.

Clearly information provision for carers using language that they will relate to is extremely important in terms of more effective targeting.. It may not be helpful to use the word "carer" at all on public - facing information but instead referring to people who help to care or supportothers or, where appropriate, parents. All service commissioning strategies should consider and make plans for the information requirements of carers and should consider how clear signposting to this information can be achieved post diagnosis and throughout the caring journey so that carers can help prepare themselves for their caring role.

Re-ablement

Re-ablement services are available countywide and offer people periods of intensive support following an illness or disability to enable individuals to regain independence and confidence. Carers are key partners in sustaining the re-abling process after the re-ablement package has finished and helping to prevent readmissions to hospital services. It is important that carers are fully aware of what re-ablement offers and are routinely involved as part of the re-ablement process and are offered appropriate information and signposting to carer support.

Acknowledgement and Involvement

Recognition and acknowledgement of a carer's expertise and involvement contributes significantly to the development of well co-ordinated and effective support packages. Improving carer awareness is key to ensuring that staff in health, social care and partner agencies recognise and support carers as part of their everyday work. Feedback from frontline staff attending carer awareness sessions run by Warwickshire County Council in 2009/10 emphasised the value to their personal practice of having a better understanding of the carer's role. For Young Carers, it is essential that schools and colleges work to identify young carers and promote information to assist them in self-identifying and seeking support.

The Adult Social Care Customer Assessment processes have been revised with the involvement of customers and carers and fully recognise the carer's input and considers the impact of the caring role on the carer and the support required to sustain the caring relationship. The Carers Assessment provides an opportunity to acknowledge the carer as an inidividual and to reflect on their life outside the caring role.

Involving carers in designing local care provision demonstrates our recognition and acknowledgement of the carer's role and expertise. Examples of this approach include involvement of carers in all stages of the commissioning process from service reviews to tender evaluation. We have developed an extensive register of interested carers who are willing to work with us in planning and reviewing services and social care processes. Further improvements can be achieved by working more collaboratively with other stakeholders and commissioning partners to prevent duplication in consultation and to maximise available resources.





What we will do to achieve Priority 1:

Actions

- All local strategies will consider opportunities appropriate to their client group or purpose to facilitate early identification of carers and signposting to carer support services and sources of information
- Provide good quality information about caring for specific conditions/illnesses which is easily
 accessible within appropriate health, social care and community settings including GP
 practices, hospitals and children's centres.
- Provide good quality information about available services and how to access them and ensure that this is widely promoted through partner agencies including employers.
- Offer signposting and information for carers of people approaching the end of their lives through training and awareness raising of social care staff.
- Promote identification and provision of information to carers during the period that their cared for person is using reablement services
- Collaborate with commissioning partners to maximise the outcomes from consultative and engagement activities and reduce duplication
- Continue to monitor carers' involvement in individual care planning and the outcomes achieved
- Work collaboratively with schools and colleges to facilitate early identification of Young Carers and signposting to appropriate support.





Priority 2

Enabling carers to fulfill their educational and employment potential – ensuring that carers are not financially disadvantaged and that children will be thriving and protected from inappropriate caring roles.

Carers make up over 12% of the national workforce, equating to 1 in every 7 employees¹¹. The refresh of the National Carers' Strategy¹² identified that 90% of working carers are aged 30 and over and in their prime employment years. The peak age for caring is 45–64 when many employees will have gained valuable skills and experience.

For carers who are in employment, taking on a caring role often results in reduced hours, or, for some, the need to move to a closer work location or give up work completely. It may also impinge on their opportunities for career advancement if it is perceived their caring responsibilities could negatively impact on their flexibility and availability. This is particularly the case where a carer's working hours need to accommodate the person who is reliant on them for support such as a disabled child or frail elderly parent.

For many carers the financial impact of giving up work to care is significant. It can plunge families into difficult economic circumstances through choices and decisions made early on that are reactive to the intensity and emotional upheaval of the caring role, rather than as part of a planned and informed approach.

The most recent national survey of carers identified that over a guarter of all carers' ability to take up or stay in work had been affected by their caring responsibilities with nearly 40% having to leave work altogether and over a third having to reduce their hours. 13 Directly related benefits such as Carers Allowance are not set at a level which equates to a realistic alternative to the financial rewards from employment and the Personal Social Services Survey of Adults Carers in England 2009/10 found that 41% of carers had experienced financial difficulties as a direct consequence of their caring role.

Providing unpaid care to older people and people with disabilities is costly. Many unpaid carers leave employment and experience costs to themselves in terms of foregone earnings. Initial findings from a new study at the London School of Economics and Political Science (LSE) now show that carers leaving employment also involves high costs to the public purse. The study shows that the public expenditure costs of carers leaving employment in England amount to around £1.3 billion a year. 14 This figure is based only on the costs of Carers' Allowance and lost tax revenues on foregone incomes. The figure would be even higher if other benefits and lost national insurance contributions on foregone incomes were also taken into account.

¹³ Survey of Carers in Households 2009/10



Warwickshire

¹¹ Carers UK, 2009

¹² Recognised, Respected and Valued: next steps for the carers' strategy, Dept of Health, 2010

25% of respondents to the most recent survey of carers in Warwickshire indicated that they were economically inactive due to their caring role. In some areas of Warwickshire as much as 8% of the ward population are combining full-time work and caring (Coleshill North & South, Leek Wootton, Sambourne). Additional factors, such as the rural nature of parts of the county are also significant for carers as this can affect the supply of services in their locality, the availability of transport and the availability of local work opportunities.

A national survey found that over two-thirds of carers who wished to return to work felt that the factor likely to help most in taking up paid employment was flexibility in hours¹⁵. Other significant factors were the ability to work from home and access to affordable replacement care. Carers are restricted in many cases from pursuing employment that would require overnight absences or working away from home. Awareness of the right to request flexible working was low among carers with over three-quarters not aware of this right.

Due to the wide dispersal of families there are an increasing number of carers who find themselves providing care for someone who may be living in another part of the town, region, country or even the world. He Nearly half of carers in this situation indicated that that their work had been affected and that they felt tired, stressed and anxious due to their caring role. Nearly a quarter had changed their working pattern to care and 24% had reduced their hours or seniority to cope with their caring role. 43% cited flexible working arrangements as the single most commonly available support with around a quarter benefiting from employer-provided support networks or stress management support. A clear majority of distance carers identified information about help and services for the person they care for as a priority.

For carers to be able to make informed choices about combining work and caring and to understand the financial implications of those choices they need good quality information about their employment rights, appropriate support services and replacement care at a very early stage in their caring role. Employers would also benefit from an increased awareness of the options that might be available to their employees.

Young Carers and Young Adult Carers

Carers who are under 16 and in the 16-34 age group are those most likely to have their education affected by their caring role.

Studies have found that the negative impacts of caring on young carers are largely due to a lack of adequate health and social care for disabled/ill adults although other factors include the nature of illness/disability of the care recipient, family structure, age, gender and cultural considerations. There may also be a disinclination on the part of a young carer's family to access support services due to an apprehension of what social services interventions may result. ¹⁷

Young carers may routinely be involved in domestic chores, general caring (giving medication, assisting with mobility), personal care and emotional support. In some families, as well as one or more of these caring tasks, young carers will also provide child care for younger siblings. 18 Young

¹⁸ C Dearden, 2001





¹⁵ Survey of Carers in Households 2009/10

¹⁶ Caring at a distance:bridging the gap, Carers UK, 2011

¹⁷ Survey of Carers in Households 2009/10

adult carers may find it difficult to fit their caring responsibilities around post 16 education, apprenticeships, or a job.

Research carried out into young carers¹⁹ of school age found that the impact was significant in all age groups with 28% of 5-15 age group experiencing educational difficulties or missing school. A consequence of a fragmented education manifests itself in the disproportionately high numbers of young carers who go on to work in the care industry due in part to being unable to achieve educational qualifications that would equip them to seek other work and partly to their caring experience having shaped their expectations of what they are able to do.²⁰

Early identification of young carers is key to the success of supportive interventions. There is significant focus within this Strategy on schools and other professionals working with young carers to ensure that staff are sufficiently skilled in recognising the signs and symptoms which could point to a child/person having a caring role. GP Practices are now required to identify carers within their practice and doctors need to be aware of the welfare of children and young people when they see patients who are cared for by children and young people.

A Whole Family Approach to supporting young carers, bringing together all key agencies including health, social care, education and the voluntary sector will maximise opportunities for securing good quality outcomes. Members of staff from these services are often best placed to identify young carers and enable them and their families to access appropriate and timely support.

Warwickshire Young Carers Project has recently been successful in bidding for funding to support the "Caring to Succeed Project", a three year programme that will champion the personal development needs of young carers aged 13 – 25. The project aims to give young carers the same chances as their peers and will include

homework clubs, drop ins at local colleges and personal action plans. It will work in close partnership with other local initiatives including Warwickshire Fire and Rescue to deliver their FLARE programme, with Warwickshire Association of Youth Clubs (WAYC) to deliver Peer Mentoring and other personal development programmes, and with Warwickshire Clubs for Young People (WCYP) on personal development skills and qualifications with the aim of providing young carers with useful life skills.

The Warwickshire Joint Health & Wellbeing Strategy 2012 consultation document identifies the importance of facilitating access to employment as a means of promoting good health and wellbeing for carers and it would be helpful to see this extended to include the needs of young carers to have access to a good education during school and training years.

There must also be a true and active commitment by all agencies to work co-operatively to ensure young carers and their families know where and how they can access support and feel confident to do so.

²⁰ Becker, 2009





¹⁹ Becker, Dearden, 1998

What we will do to achieve Priority 2:

Actions

- Develop a communication strategy with key statutory and voluntary sector partners and employers to ensure that working carers are aware of their right to request flexible working and that information about combining work and caring is widely available through employers and carer support services
- Scope with partner agencies a wider range of flexible and affordable support and care replacement options that are effectively marketed to carers to enable them to take up employment and education opportunities
- Work with schools to ensure that each school has a designated staff member for young carers who will play a crucial role in improving outcomes for this group of vulnerable children during their educational years.
- Ensure that key partner agencies are aware of, and committed to whole family working
 practices through the adoption of agreed young carer pathways and referrals and support
 protocols that underpin the memorandum of understanding between adult and children's
 services.
- Inclusion of Young Carers in the "Schools and Training" part of the Warwickshire Joint Health & Wellbeing Strategy
- Work with colleges, local universities, private sector and voluntary organisations to give consideration to the specific needs of young and adult carers and to provide opportunities to develop skills and access to employment.
- Equip social care teams with information to aid carers wishing to retain their employment or, where carers are wishing to re-enter the job market, to refer to Job Centre Plus.





Priority 3

Personalised support for carers and those receiving care, enabling them to have a family and community life

The national drive towards the transformation of adult social care, in particular moving towards more personalised services, has highlighted the need for carers and customers to have more choice and control over the services and support they receive.

It is important that carers as well as the customers they support have access to a personal budget when they have been assessed as having eligible needs and that carers are able to exercise choice and control in the use of their budget so that they are supported to care in the most appropriate way.

In addition carers need to be involved with the support planning of the person they care for in order that they can support their cared for person with decisions around their social care and support arrangements and to help ensure that decisions made by the customer are not having a negative impact on the carer in terms of service delivery.

Warwickshire County Council's adult and children's social care services are committed to a whole family approach. This ensures that the initial contact with families identifies all those in need of support and considers the caring roles being undertaken by adults and children when assessing for, and allocating, support services.

The Department of health report on *Carers and personalisation: improving outcomes (2010)* highlights the effectiveness of a whole family approach when conducting social care assessments. It states that although personalisation and the drive to implement self directed support assessments is important "working with carers as partners and taking a collaborative approach enables the contribution of carers to be a positive element in working towards a support plan and not a punitive method of reducing payment". This point specifically underlines the importance of not only taking account of 'social capital' as part of a customers self directed support assessment but also recognising the role and value of a carer by including them in the assessment and care planning process and ensuring that support and services are also available to them, where needed to sustain this caring relationship.

The recently revised Self-Assessment Questionnaire and Support Plan for customers in Warwickshire aims to identify the needs and desired outcomes of the customer. It also considers the role undertaken by the carer and the impact of that care-giving on the carer to determine the need for breaks or replacement care which form part of the customer's support plan and contribute to the framework needed to maintain the caring role.

Where the carer is employed and wishes to retain their employment, or where a carer wishes to take up work, the assessment will help to identify the type of support required to enable this to happen. In many cases this may require the provision of replacement care and will be accompanied by appropriate referral to specialist information about carers' rights to flexible working or to training organisations, or Job Centre Plus.

Breaks from the caring role are often reported by carers as the most important thing to them to allow them to continue caring. The benefit of carers receiving breaks is confirmed by national research, for example, by Carers UK who found that those carers who were not receiving a break from their caring role were more likely to suffer from mental health problems, 36% compared to





17% of those carers getting a break²¹. Carers who do not get breaks are far more likely to fall into ill health. Support, which allows carers to take some time off can prevent them from being pushed to breaking point²².

Defining breaks or replacement care for carers has been a complex issue due to gaps within the existing legislation causing some confusion about what constitutes a carer's service, and the difference between respite and a carer's short break and who is this provided to and for. It remains in law that the provision of replacement care in the form of respite or sitting services is a service to the cared for because it includes elements of personal care and is therefore classified as a community care service. The Draft Care and Support Bill introduces welcome clarity about replacement care and identifies it as a service to the cared for but with a clear purpose of supporting the carer.

Warwickshire County Council's interpretation of replacement care is that respite care and sitting services/breaks are services to the customer and form part of the customer's personal budgets as they are services directly delivered to them even though the purpose of the replacement care may be to support the carer. This is in line with the proposed new draft legislation. From April 2012 the charging policy in Warwickshire was changed to make all replacement care services have been subject to charges and are costed as part of the customer care package.

A Resource Allocation System (RAS) for carers has also been developed. The main aim of this is that services to carers in Warwickshire can be provided in a fair, clear and transparent manner. Although the budget allocation from a carer's RAS will be relatively small these will be used to directly support the carer's needs in their own right where they see fit. Where it works well carers report a creative use of the money and confirm that the opportunity to use funding flexibly meets their own individual needs.

To facilitate identification and provision of support to carers at the earliest opportunity it may be helpful to explore extending the power to conduct carers' assessments to colleagues within health services and this is identified as a specific action for scoping within the delivery plan.

Following a carer's assessment, if the impact of caring on the carer is assessed as substantial or high, they may be provided with a personal budget which will be non—chargeable and can be used for carers to purchase support for themselves in order that they are able to continue caring or to live a life outside of caring. Examples of this include: a budget to pay for the activity — where this is clearly linked to physical/emotional wellbeing e.g. gym membership, college course, counselling; and/or a budget to purchase services that will directly support the carer to continue caring and will sustain the caring role dependant on the specific outcomes a carer has identified e.g. cleaning/gardening/home maintenance service, a one-off payment to purchase a specific item. Flexibility in the use of the personal budget for the carer is paramount. This ensures that carers are able to maximise the use of this fund to have a life outside of caring.

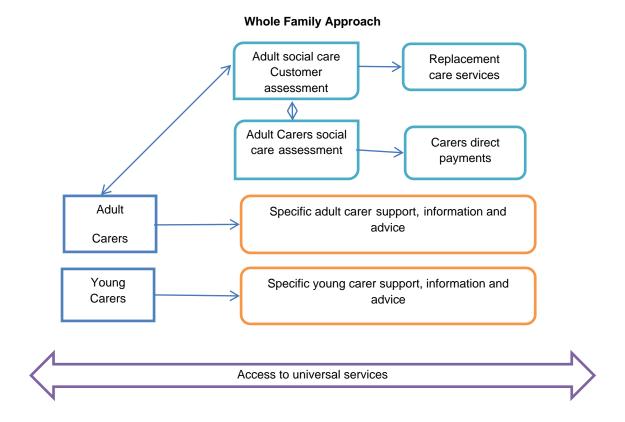
²² Survey of carers in Households (2010) NHS information centre





²¹ Hearts and minds: the health effects of caring (2004) Carers UK

The diagram below reflects how the processes relate to each other within adult social care.



Recent consultation with carers of people with Dementia and those caring for children and adults on the Autistic Spectrum has identified a need for better joint working between health and social care agencies to facilitate accessing information, diagnosis, treatment and support. Many carers are experiencing extreme isolation and an inability to live a family and community life due to the lack of appropriate support services and respite for the person they care for. Many of these carers are experiencing the symptoms of ill-health including fatigue, depression, anxiety or disturbed sleep. These issues are considered in more detail in Priority 4 – Supporting carers to remain physically and mentally well

A frequent comment during those consultations has been

"If I can get the right services for .(the person I care for) I don't need any support for myself"

It is crucial for the wellbeing of those carers that the people they care for get timely assessments and appropriate support services. It also makes better financial sense to invest in support services for the customer, which will help achieve a better outcome for both the customer and their carer and help to prevent the health impacts identified above.

Replacement Care

Good quality replacement care is crucial to maintaining the health and wellbeing of carers. Some carers are able to call on their family and friends to help out and for certain carers this is their only recourse because of a lack of appropriate care to meet the particular needs of the person they care for. Consultation carried out in Warwickshire for the review of respite services for people with learning disabilities, complex physical disabilities and autism indicates that there are gaps in





the provision of replacement care for children and adults on the Autistic Spectrum and/or with challenging behaviour.

Carers who do not have support from family and friends are reliant on replacement care service. Earlier sections of this Strategy have identified some of the reasons for carers needing replacement care and these can include: to support their employment, to enable them to attend their own medical or dental appointments, to attend to urgent business, to take a holiday or a regular planned break or even to enable them to take time off to recover their own health following an illness. In short, carers need replacement care to enable them to exercise choice and control over their lives and to do this they need it to be flexible and responsive to their requirements.

Media exposure of the abuse of adults in residential and respite facilities has served to raise carers' concerns about replacement care and this was evidenced within the consultation with people with learning disabilities, complex physical disabilities and autism and their carers, carried out in Warwickshire early in 2012,²³. Carers' top priorities for replacement care were identified as:

- Confidence and trust in the provider and staff
- Cared for person must enjoy and benefit from the service
- Good communication between staff and cared for and between the service and carers.

Carers said they judged the quality of the provision by how much the cared for person appeared to have enjoyed it, how well rested they looked, levels of personal hygiene when they returned and their willingness to use it again.

Replacement care can take many forms. Current models include residential care, home-based services (also known as "sitting services") or activity-based sessions. Assistive technology and telecare are also increasingly being used to provide more independence for carers and the people they care for through the use of equipment and aids which enable carers to feel more confident about leaving the cared for person alone for periods of time.

The range and type of replacement care will need to develop to meet increased future demand and to ensure that the needs of carers such as those who wish to retain, or return to, employment, are met both in terms of responsiveness and affordability. This demand will be driven by the new rights for carers within the draft Care and Support Bill.

There may also be benefits to carers from creative support packages for the person they care for and the ability of the cared for person to take advantage of community support initiatives. The White Paper, "Caring for our Future: reforming care and support", envisages the development of wider opportunities for citizens to become involved and supportive of their local communities. It is the Government's intention to build on existing examples of good practice and roll out volunteering options such as time banks and other approaches that enable people to share their experience. knowledge and skills with others in their community.

In the light of this it is timely to review replacement care services across all client groups to ensure that we have an appropriate range of provision to meet this challenge and this Strategy's delivery plan includes actions to take this forward.

Working for Warnickshire ²³ Review of respite services for people with learning disabilities, physical disabilities and autism, WC



Warwickshire

End of Life Caring

Carers of people approaching the end of their lives have an important role in the provision of care. They should be closely involved in decision making and recognised as having their own needs. Whether the caring role is for weeks, months or years, carers need support to ensure that this period is the best it possibly can be for the person they care for and, just as importantly, for themselves.

Carers need information about the likely progress of the person's condition and services that are available. This should include what palliative care resources can be made available to support a carer when the person they care for wishes to die at home, away from a hospice or ward setting e.g. access to a hospital style bed within the home, access to district nursing and equipment, help with bathing and other practical caring activities. They may also need emotional support and counselling during the person's life and following bereavement and access to financial information and advice.²⁴

Warwickshire's End of Life Strategy²⁵ identified carers' priorities as:

- Clear information throughout their caring role including out of hours services
- A named worker to ensure continuity of care
- An assessment of their own needs as early as possible to identify a clear pathway of support
- Confidence that their needs will be incorporated into support for those of the patient
- Access to 24 hour support which is accessible and responsive to their individual requirements
- Training to enable them to be confident care givers particularly at this sensitive time
- Emotional support.

To ensure the best possible support is offered it is important to identify carers who care for someone approaching end of life at the earliest opportunity and ensure that this information is used and shared sensitively with colleagues. Raising the awareness of social care staff to the important role they can play and providing the training and support to aid this for all staff including domiciliary care workers, social workers and their managers will be crucial in achieving better outcomes for people approaching the end of their lives and their carers.

To support adult social care workers to deliver high quality end of life care, Skills for Care has developed a number of specific qualifications and from September 2012 all the units developed as part of the new end of life qualifications will be added to the existing health and social care diplomas.

Young Carers

The 2001 Census over 1,220 were young carers. We know that this number has grown over the intervening years and will always be an underestimate of the true number of children and young people given that the census questionnaire was completed by parents, rather than children, and made no mention of conditions such as mental health, substance misuse or HIV/Aids. More recent research indicates that there are four times²⁶more young carers than are officially recognised. This would mean there are about 4,880 young carers in Warwickshire.

²⁶ BBC and University of Nottingham, 2010



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Warwickshire
County Council

²⁴ End of Life care Strategy, DH, 2008

²⁵ End of Life Care Strategy for Warwickshire, WCC & NHS Warwickshire, 2009

Nationally it is estimated that 27% of young carers (aged 11–15) miss school or experience educational difficulties. 68% of young carers are bullied and feel isolated in schools and 13,000 of the UK's young carers care for over 50 hours a week²⁷.

Whilst progress is being made in supporting young carers more needs to be done in order to achieve good outcomes for this vulnerable group of children/young people.

A whole family approach is instrumental to ensuring that young carers are protected from inappropriate levels of caring. Further work is needed to ensure that protocols between adult and children's social care services and local health services are developed to ensure that all the carers involved are considered within support plans and that the carers' input and needs, be they adults or children, are taken into account.

There must also be a true and active commitment, by all agencies, to work co-operatively to ensure young carers and their families know where and how they can access support and feel confident to do so.

What we will do to achieve Priority 3:

Actions

- All strategies working across Health and Social Care need to identify clear pathways for accessing services and make this information easily available to carers at an early stage in their caring role.
- All strategies working across Health and social care need to consider how services can achieve better joined up working practices.
- All strategies to review replacement care provision (including residential respite and short breaks) with the aim of widening the availability and range of affordable, appropriate and easily accessible provision through redesign and de and re-commissioning as appropriate.
- To facilitate early identification of people approaching end of life, and their carers, and to
 ensure timely and sensitive offers of support the introduction of an indicator on CareFirst
 home screen to be scoped.
- Future planning for the cared for develop a template for use in helping carers to plan for, and feel more confident about, the future of the person they care for
- Future planning for carers develop a template for use in helping carers to prepare and plan for when their caring role may end.
- Review the existing assessment, review and cross-referral social care processes to determine appropriateness with whole family working approach and develop new protocols as required.
- Roll out cultural and business process training for frontline staff on new customer and carer assessments.

²⁷ The Carers Trust, 2012



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Warwickshire

Priority 4

Supporting carers to remain physically and mentally well

Over 80% of carers report that caring has had a significant negative impact on their physical and/or mental health²⁸ and nearly 40% have had to put off medical treatment because of their caring role. Carers have cited the lack of practical and financial support as contributing to this impact with uncertainty about the future of local services and reductions in public spending causing additional stress and anxiety. A frequent comment during the recent consultation carried out in Warwickshire²⁹ was that "Social services are only interested in crisis situations."

The intensity of the caring role, living in the same household as the cared for person and the length of the caring role have all been found to be signifiers of poor health in carers with two thirds of carers who provide over 20 hours per week reporting adverse effects on their health. Over half of all carers reported that their health had been affected in some way with the most common effects being: fatigue, feeling stressed, having disturbed sleep and feeling irritable. Carers also reported experiencing depression and physical strain and the need to contact a GP to meet their own health needs.

Just under half of all carers indicated that caring had an impact on their leisure or social activities. This research also found that 27% of all carers reported that they had been caring for over 10 years with 1 in 8 caring in excess of 20 years.

Recent Government policy has highlighted carers as a group experiencing comparative poor health. Research on populations of carers has consistently demonstrated that caring has a pronounced adverse effect on psychological health with 40% of carers presenting significant distress and depression levels³⁰

Recent consultation within Warwickshire ³¹ indicated that 44% of all carers felt they were not looking after themselves well enough with half of this number reporting that they were neglecting themselves and citing the main reasons being the need to put others first, lack of sleep, feeling anxious and no time to attend to own health concerns.

"Delaying my operation as have to look after my child, I don't get enough sleep – when I have spare time I need to catch up with housework..." Warwickshire Carer

Carers who provide over 20 hours of care per week and who lived with the person they cared for were more likely to experience a significant impact on their health ³².

"Because my wife and I have cared for our son for 50 years it has become the norm to put him first and we don't really think of ourselves." Warwickshire Carer

³² Survey of Carers in Households 2009/10.





²⁸ In Sickness and in Health, Carers UK, 2012

²⁹ Carers Questionnaire, WCC, 2012

³⁰ Supporting Carers Action- An action guide for GPs and their Teams. Royal College of GPs and PRTC, 2011

³¹ Carers Questionnaire, WCC, 2012

Carers providing more than 20 hours of care per week over prolonged periods are twice as likely to experience psychological distress over a period of two years than non-carers and the risk of distress increases proportionately in line with the amount of time devoted to caring each week. The adverse psychological effects associated with caring continue to be evident after the caring role has ceased.

The effects of caring on physical health can include back injury (reported by one fifth of carers in one survey) and high blood pressure (10%). Providing high levels of care is also associated with a 23% higher risk of stroke.

The incidence of intensive caring appears to be much more widespread than previously thought leading to many more carers being potentially at risk of ill-health. The General Household Survey 2009/10 found that 48% of carers surveyed provided care for 20 hours or more per week, 30% of carers provided care for 35 hours or more per week and 22% of carers provided care for 50 hours or more per week. This compares to 10% of carers who were providing over 50 hours of care per week as identified in the 2011 Census.

Regular health checks can help to optimise carers' health and wellbeing by highlighting issues which can be dealt with at an earlier stage. Recent health checks carried out in Warwickshire as part of an initiative involving joint working between Guideposts Carers Support Service and some GP practices revealed that between one third and a half of all carers taking part needed a follow up appointment with their own GP to address health issues flagged up by the health check. Not all GP practices offer health checks for carers. Fewer than a quarter of carers who responded to the Carers UK survey reported that their GP had offered a health check.

The new Clinical Commissioning Groups offer opportunities for social care and health to work together to promote better health and wellbeing for carers. It is encouraging that the South Warwickshire CCG's Commissioning Intentions includes specific mention of carers:

"These commissioning intentions have been developed by the clinical leaders in South Warwickshire. They are based on the priorities identified in the Warwickshire Joint Strategic Needs Assessment and Health and Wellbeing Strategy, national and SHA priorities, QIPP work streams and views of local GP practices, patients and carers".

Multiple and Long-term Caring Roles

Although most (83%) carers provide care for one person only the numbers of those caring for two or more are increasing with 14% caring for two people and 3% looking after 3 or more suggesting an increased intergenerational element with carers caring for a child and also an older person. Those carers who are actively caring for more than one person are among those who are most at risk of health problems, as are those who have a long term caring roles spanning decades.³³

"Because I care for my very ill husband I do not get a break from caring even when my grandson is in respite". Warwickshire Carer

"I have never had a break from caring, so I haven't taken a holiday or rest for over 30 years." Warwickshire Carer

³³ Survey of Carers in Households 200910.





"I have not been on holiday for 8 years due to parent and now son, both of whom need 24 hour care." Warwickshire Carer

The impact of long-term and multiple caring for people who fall below the threshold for services should not be underestimated, nor caring for those who are unable, or do not wish, to access community services which might give their carer a break. These carers are also prey to disturbed sleep, fatigue and a lack of breaks and it is timely to review our approach to supporting these carers to minimise the negative health impacts.

"I always put my daughter's needs first, when she gets angry she slams doors, puts holes in walls within the house. I feel tired and very drained and feel like I shout all the time" Warwickshire carer

Carers have told us that practical support and the opportunity to take breaks can make a huge difference to their physical and mental health.

Two thirds of carers caring for over 20 hpw indicated that replacement care would be required if they were to take a break for a couple of days. The majority of those (91%) said that if they were to take a break they would need a relative's support with this with only 6% using a paid worker.

Respondents to the recent Warwickshire carers questionnaire³⁴ revealed that just under half were able to take a regular break with 49% of those indicating that support enabling them to do this came from family and friends. Comments from carers indicate that they consider respite and breaks to be expensive and some carers of people with dementia or autism or other forms of challenging behaviour feel that behavioural issues prevent anyone other than family (where this exists) providing replacement care.

42% of carers have not had a break of 2 days or more since they began caring. These carers are most likely to be over 65, living in same household, providing over 20 hours per week, with bad or fair health and on low incomes.³⁵

Emotional wellbeing

Caring for someone with a serious illness or disability has its own emotional impact and managing the practicalities of caring such as: medication, medical appointments, benefits, and social care support can be daunting and stressful. It is perhaps not surprising that in terms of emotional wellbeing only a fifth of carers who responded to the Warwickshire carers' survey felt able to describe themselves as happy and fulfilled most of the time and 70% of carers felt they were not confident about the future.

"You cannot feel happy/fulfilled constantly when you have no idea what the future holds."

"I am healthy and fit at present, but will shortly be 65 years old and am worried about the future re my son and wife who both have mental health issues".

Future Plans

Carers would welcome the opportunity to plan ahead, to consider the future of the person they care for and their own. This reflects one of the outcomes from the Learning Disability Strategy to

³⁵ Survey of Carers in Households 200910





³⁴ Carers Questionnaire, WCC, 2012

develop future plans which will consider the longer term needs of the person they care for taking into account accommodation, legal guardianship and financial security. Carers have also identified a need to plan for their own future when they may no longer be in a caring role and may need to be prepared to re-enter employment, training or education.

Housing Related Support

Where and how carers, and the people that they care for, live can have a major impact on their health and wellbeing. Improving access and mobility within the home through the use of assistive technology or Disabled Facilities Grants or relocating to more appropriate supported accommodation such as Extra Care

can be a very practical way of increasing the independence of of customers and reducing pressure on carers. Access to information about housing related support options is key for all agencies working with carers and carers themselves.

Young Carers

Being a young carer can have detrimental effects on young people, including problems at school, health problems, emotional difficulties, isolation, lack of time for leisure, feeling different, pressure from keeping family problems a secret, difficulties with transition to adulthood, lack of recognition and feeling they are not being listened to.

In the first study of its kind, the Children's Society and the Open University School of Health and Social Welfare found that 70% of former young carers suffered long-term psychological effects, and 40% had mental health problems.

The psychological effects included problems relating to people in a social context and difficulty making friends.

Many miss out on playtime and end up adopting a parental role, which can make it difficult for them to adjust to situations where they are expected to behave like children, such as at school.³⁶ Research indicates that relatively small numbers of young carers are currently being identified or assessed for support. The reasons for this may include blurred boundaries of responsibility between adults and children's services; a lack of awareness among many professional groups of young carers' needs and concerns; and young carers' own lack of awareness of their entitlements, and their reluctance to seek formal help.

The research consistently reports positive feedback from young carers about young carers' projects. In this setting many young carers consider their problems and experiences to be valued, understood and recognised. They prefer support that is non-intrusive and provided by individuals and organisations other than statutory services.

Researchers questioned 66 former young carers about the effects they thought their childhood experiences had had on them in later life, 28% said they suffered physical health problems, such as bad backs due to lifting relatives.

³⁶ Bilsborrow, 1992; Aldridge and Becker, 1993a, Dearden and Becker,
1995, 1998); Dearden and Becker, 2000); Aldridge and
Becker, 1993a); Becker, Aldridge and Dearden, 1998; , 1992; Dearden and Becker, 1995, 1998; Marsden, 1995;
Dearden and Becker, 1998



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In other local authority areas school nurses already carrying out health checks for looked after children used exactly the same format for young carers. Part of this approach included asking them more about the practical tasks they undertake and their own health and hygiene. This has revealed incidents of age inappropriate caring roles such as moving and handling of their parent/or sibling and also that some young carers own needs for dental or eyesight checks or general welfare were being neglected.

What we will do to achieve Priority 4:

- Work with individual GPs and the Clinical Commissioning Groups to facilitate regular health checks for carers and access to appropriate counselling support.
- Countywide training for carers in managing care for people with specific conditions/illnesses such as Autistic Spectrum Disorder, Dementia, Mental Illness, etc. All strategies need to consider practical training for carers within their proposals for workforce development and training.
- Support for the cared for is provided to enable carers to attend support groups where no other replacement care is available
- Carers' health issues to be recognised more widely within the Joint Health and Wellbeing Strategy
- Ensure that appropriate whole family approaches are adopted to ensure that cared for people receive appropriate levels of service and that carers of all ages are able to access breaks
- Work with school nurses to provide health checks for young carers
- Future planning for the cared for to enable carers to feel confident about the future of the person they care for
- Future planning for carers to enable carers to prepare for when their caring role may end.
- Ensure that a whole family approach is used when making transition arrangements
- Carer's Assessments will offer the opportunity to focus on the carer's health and wellbeing with Direct Payments being offered to eligible carers to creatively support related outcomes eg through gym membership, fitness classes, etc.
- Provision of county-wide support offering emotional, 1 to 1, peer and group support, relaxation and coping strategies, and practical management of the caring role eg moving and handling
- Ensure that schools and colleges are aware of their role in offering appropriate interventions to young carers in collaboration with partner agencies such as Young Carers Project, Children's Services, etc.





Section Three

Appendix 1: Key demographics

In the 2001 Census 53,221 people in Warwickshire identified themselves as providing unpaid care for another person. The gender split indicated that 58% of these carers are female, which is line with the national trend.

Of these over 1,220 were young carers. We know that this number has grown over the intervening years and will always be an underestimate of the true number of children and young people given that the census questionnaire was completed by parents, rather than children, and made no mention of conditions such as mental health, substance misuse or HIV/Aids. More recent research indicates that there are four times³⁷ more young carers than are officially recognised. This would mean there are about 4,880 young carers in Warwickshire.

The overall figure for carers is in line with the national average of 10% and slightly lower than the regional figure overall. However, there are differences across the districts that make up the county with North Warwickshire (11.4%) and Nuneaton and Bedworth (11%) indicating a higher number of carers in those areas.

The 2001 Census identified 9,444 (17.7%) carers providing over 50 hours of unpaid care per week. More recent research³⁸ suggests that this figure could be doubled and that carers regularly providing over 20 hours per week were more likely to experience an impact on their own health.

Nationally, most carers are caring for just one person, however, 17% are caring for two or more people. The group most likely to be providing care for two or more people are those aged 45-64. The survey of carers in Warwickshire carried out in 2012 found that 89% of respondents care for one person, 7% care for 2 and 5% care for 3 or more and that 84% of the respondents live with the person they care for – a category of carer most likely to experience a significant impact on their own health.

Over half of carers (55%)³⁹ have their own health problems including physical disability/impairment, sensory impairment, mental ill-health and learning disability About 1 in 5 adults with a long-term limiting illness are also carers⁴⁰.

A comparison of carers with the general population⁴¹ found that significantly fewer carers described their health as good (62% against 76% in the general population) with only 54% of those who were caring for someone in the same household and 52% of those caring for more than 20 hours per week describing their health as good. Those aged over 65 are most likely to provide

⁴¹ Health Survey for England Adult trend tables, 2008





³⁷ BBC and University of Nottingham, 2010

³⁸ Survey of Carers in Households 2009/10

³⁹ Personal Social Services Survey of Adult Carers in England 2009/10

⁴⁰ Survey of Carers in Households 2009/10

care for someone in the same household. Two-thirds of carers reported feeling tired, over half had disturbed sleep, half had feeling of stress and over a third depressed.⁴²

Profile of Carers Accessing Social Care Services

Table 1. 1: Breakdown of carer numbers by intensity of caring and by district (Census 2001)

	No. providing unpaid care	% population providing unpaid care	No. carers providing care 50+ hrs per wk	% carers providing care 50+ hrs per wk
North Warwickshire	7,070	11.4%	1,441	20.3%
Nuneaton & Bedworth	13,212	11.0%	2,906	22%
Rugby	9,059	10.3%	1,534	16.9%
Stratford on Avon	11,532	10.3%	1,716	14.8%
Warwick	12,348	9.8%	1,847	14.9%
Warwickshire	53,221	10.2%	9,444	17.7%
West Midlands	558,421	10.6%	119,277	21.3%
England & Wales	5,217,805	10.0%	1,088,336	20.1%

Table 1.2: Breakdown of carer numbers showing distribution of carers known to Adult Social Care by district

pcl District	Number Of Carers	% Number Of Carers	Number Cared For	% Number Cared For
Unknown	1520	31.44%	1532	30.60%
North Warwickshire Borough	442	9.14%	461	9.21%
Nuneaton & Bedworth Borough	833	17.23%	877	17.52%
Rugby Borough	735	15.20%	763	15.24%
Stratford-on-Avon District	637	13.17%	658	13.14%
Warwick District	668	13.82%	715	14.28%
Total	4835	100.00%	5006	100.00%

⁴² Personal Social Services Survey of Adult Carers in England 2009/1





There appears to be some degree of North-South pattern with those in the North providing less low-level caring and more high-level caring and the reverse being true in the South. There are particularly high numbers of carers in Nuneaton and Bedworth who are providing more then 50 hours of unpaid care per week and maintaining paid employment.⁴³

Those who are providing more then 50 hours of care each week are split fairly evenly across the ten year age bands 35 – 75 years, with a slight peak in the 55 to 64 age group. It should be noted that about 15% of carers are actually over the age of 75 years and hence likely to themselves be in poorer health.

Nuneaton and Bedworth have a greater number of people providing over 50 hours of care than the rest of the County, a large proportion of which are from minority communities. This picture is reflected in the figures from Adult Social Care, which indicate that there are more people in receipt of social care support in the north of the county. However, there are higher numbers of carers over 70 years of age in the districts of Warwick and Stratford.

The higher intensity of the caring role in Nuneaton and Bedworth and to some extent North Warwickshire is also illustrated in the tables showing the carer support levels reported in the customer's "My Assessment" questionnaires. See tables on pages 34-35.

The following profile emerged from the recent Warwickshire Carer Survey⁴⁴:

Just under 540 carers responded to the carers questionnaire. Approximately half of all respondents felt they had had a health assessment carried out by a nurse and the majority felt that they had had their concerns as a carer taken in to account.

A third of all respondents felt that the person they care for had received a social care assessment and again the majority felt that they had had their concerns as a carer taken into account. A third of all respondents felt they had received a carer's assessment.

Half of the respondents overall indicated that they were able to take a regular break with 49% indicating that the support that enabled them to do this came from family and friends.

68% of carers said they were not confident about the future, with the majority of respondents citing uncertainty about the quality of care for the person they care for as being the main reason for their anxiety. Those carers who were most concerned about the future were parents/carers of people with Autistic Spectrum Disorder (73%).

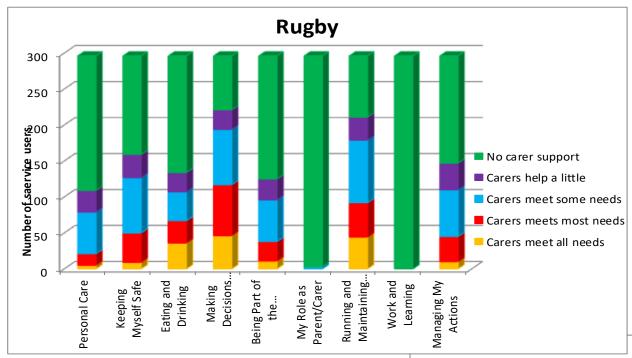
25% of respondents overall indicated that they were currently not working due to their caring role. However, this increased to 40% for carers of people with Autistic Spectrum Disorder.

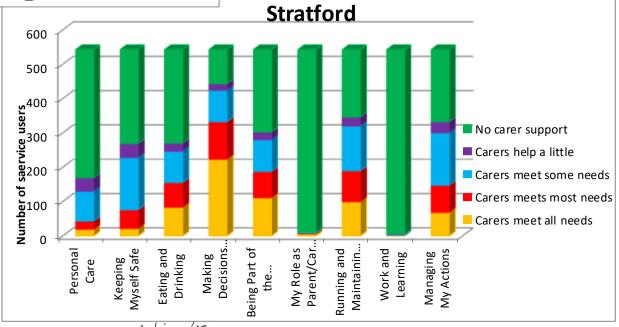
⁴⁴ Carers Questionnaire, WCC, 2012





⁴³ JSNA.2011.

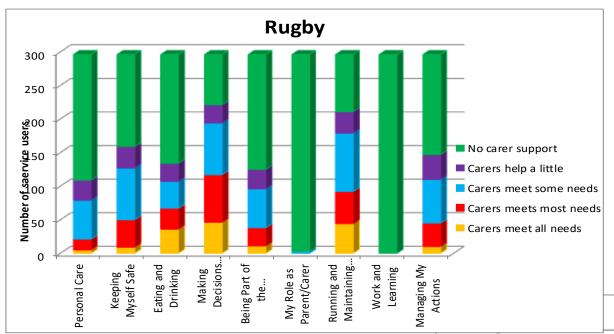


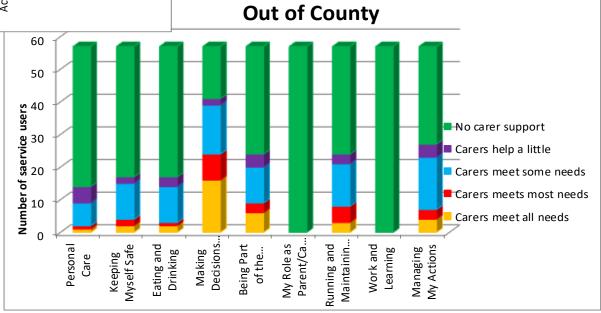








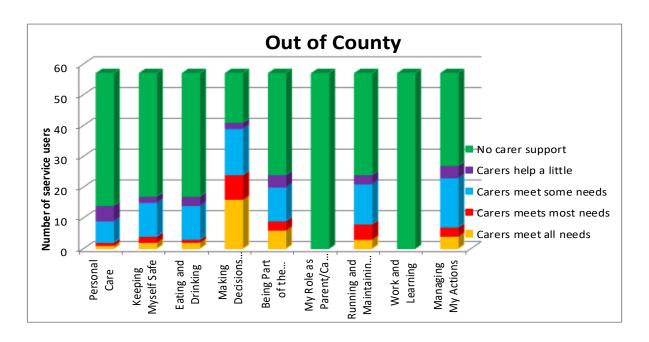


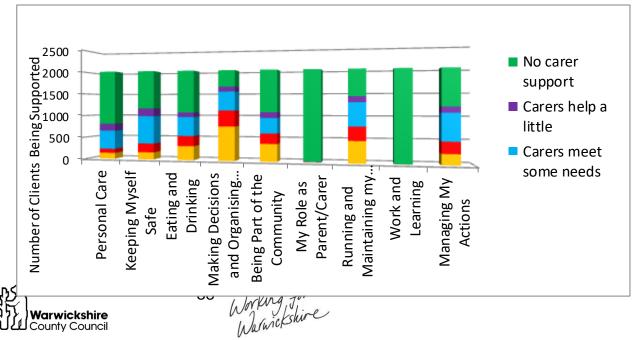








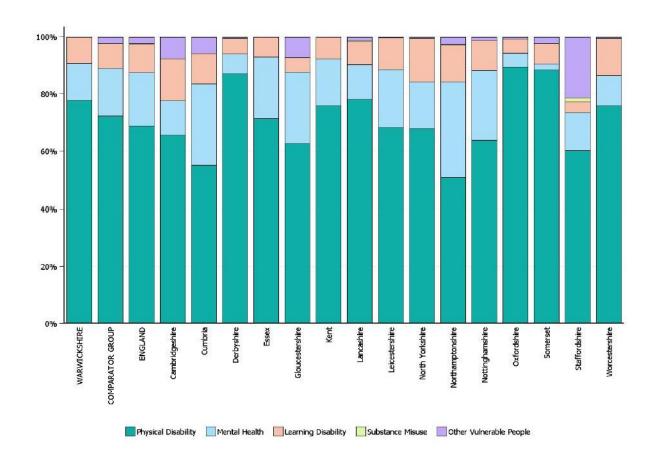






Carers receiving services, information and/or advice

The following table shows the percentage of carers who received services, information and/or advice during the year, by primary client group of the cared for person







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Ethnic Profile of Ethnic background of Carers Questionnaire respondents

Analysis of the ethnic background of those carers who responded to the survey indicates a lower representation of people in all non white categories.

Ethnic Group Profile

	Carers Strategy Questionnaire Ethnic Group profile	Warwickshire Ethnic Group profile
White: British	91.0%	88.3%
White: Irish	2.2%	1.2%
White: Other White	2.6%	2.7%
Mixed: White and Black Caribbean	0.0%	0.5%
Mixed: White and Black African	0.0%	0.1%
Mixed: White and Asian	0.2%	0.4%
Mixed: Other Mixed	0.2%	0.3%
Asian or Asian British: Indian	2.0%	2.9%
Asian or Asian British: Pakistani	0.4%	0.8%
Asian or Asian British: Bangladeshi	0.0%	0.2%
Asian or Asian British: Other Asian	0.2%	0.4%
Black or Black British: Black Caribbean	0.4%	0.5%
Black or Black British: Black African	0.4%	0.5%
Black or Black British: Other Black	0.0%	0.1%
Chinese or Other Ethnic Group: Chinese	0.0%	0.5%
Chinese or Other Ethnic Group: Other	0.2%	0.5%

Ethnic background of carers who have received social care assessments, services and/or information.

NB: Carer's Ethnicity for clients with current agreement

Carers Ethnicity	Number In	%	% Excluding
	Group		Unkown group
Caribbean	14	0.18%	0.49%
Chinese	1	0.01%	0.03%
Gypsy/Roma	1	0.01%	0.03%
Indian	90	1.14%	3.13%
Other Asian	11	0.14%	0.38%
Other Ethnic Group	9	0.11%	0.31%
Other Mixed	2	0.03%	0.07%
Other White	30	0.38%	1.04%
Pakistani	5	0.06%	0.17%
Unknown	5049	63.69%	
White & Asian	3	0.04%	0.10%
White & Blck Carib	5	0.06%	0.17%
White British	2676	33.75%	92.95%
White Irish	32	0.40%	1.11%
TOTAL	7928	100.00%	100.00%





The above tables appear to indicate that our recording of carers within social care needs to improve if we are to have an accurate profile of carers in Warwickshire on which we can base our commissioning intentions. They would also suggest that we may need to improve targeting of certain minority ethnic communities to ensure that take up of services reflects that profile. Actions to improve recording of carer data and better targeting of information and services are included in the Delivery Plan.





Appendix 2: National & Legal Context

A summary of the current key policy and legislative framework is given later in this section. However, it feels appropriate to give priority to the two draft bills out to consultation which, if enacted, will substantially change, for the better, how carers are supported. These are:

- Draft Care and Support Bill; and
- Draft Social Care (Local Sufficiency of Supply) and Identification of Carers Bill

The **Draft Care and Support Bill** places the promotion of individual well-being as the driving force behind care and support and aims to pull together previous social care legislation into one unified act with a simplified approach and more consistent pathways. It also provides the legislative framework for recent policy developments such as personalisation. The Bill will represent a wholesale change in the way that carers, disabled people and older people are supported by communities.

It is anticipated that the legislation will come in the fourth session of parliament i.e. 2013/14, but this will not be confirmed until the Queen's Speech in June 2013. Implementation would then be in 2015. There will be costs associated with carers' new rights which are provisionally planned for 2015.

The key elements are as follows:

- A duty on Local Authorities to provide an information and advice service to help people
 understand how the care system works, what services are available locally and how they can
 be accessed. Local Authorities would also have a duty to ensure a diverse range of quality
 services to meet needs and to work with other local organisations to integrate services with the
 aim of promoting well-being and improving quality and outcomes.
- A duty on Local Authorities to take a proactive approach, make earlier interventions and provide services which are intended to prevent, delay or reduce people's needs for care and support. The aim will be to prevent or reduce dependency rather than responding to crisis situations.
- Assessments will focus on the needs and desired outcomes of the cared for person and their carer(s) rather than on the services to be provided. The assessment must be carried out without regard to whether the individual is eligible for services and eligibility will be determined by a national threshold rather than by individual local authorities.
- Local Authority arrangements for charging will be standardised and transparent. Deferred
 payment options ie repayment of care charges from the sale of the customer's home are to be
 routinely offered with Local Authorities likely to be able to charge interest on the deferred
 payment.
- There will be a single, consistent route to establishing entitlement to care and support for adults.
- The personalisation approach whereby individuals are offered an assessment of their needs followed by a care and support plan and a personal budget is defined in this legislation.
- Carers will, for the first time, have a legal right to have a carer's assessment of their needs without having to meet the requirement that they are providing substantial and regular care. The duty on Local Authorities regarding carers will be comparable with that for the people they care for. There will be a new framework for assessing eligibility for support which will be set out in regulations. There will be a new duty on Local Authorities to meet carers' eligible needs and to review their care and support plan regularly to ensure that their needs continue to be met.





Carers will also have new rights to be consulted in relation to the assessment and support plan of the person they care for and to have a copy of the support plan.

- The draft Bill clearly states that local authorities would be required to meet the eligible needs of carers, either by providing services to the cared for or to the carer. Services which might prove most helpful to carers could include those which give the carer a break from their caring responsibilities such as help with housework or gardening, purchase of a laptop to help them stay in touch with family and friends, or gym membership to support the carer's own health and wellbeing. The draft Bill also allows for the carer's needs to be met by providing support directly to the person they care for through replacement care to enable the carer to take a break.
- Young carers under the age of 18 who care for adults will be supported by children's services rather than adult care and support. At the age of 18 the responsibility will switch to adults services although adult services can be brought into transitions planning before the young carer's 18th birthday at the carer's request. There will also be a new duty to continue any children's services which a young carer is receiving past the age of 18, if appropriate adult care and support is not in place.
- New provisions in the draft Bill will enable parent carers to be assessed under adult law as well as children's law enabling them to access services that they may currently be unable to use.
- Adult safeguarding will be strengthened by the creation of a clear framework of responsibilities and governance arrangements, including the establishment of a Safeguarding Adults Board to support a strategic and integrated multi-agency approach.
- Development of a new structure for overseeing the education and training of the future healthcare workforce and ensuring supply of appropriately qualified staff keeps pace with health service needs.
- Strengthening the Health Research Authority and enabling it to function more effectively, achieve a unified approval process for research and promote a proportionate approach among those involved in research. Benefits arising from this are expected to include reduction in duplication and red tape and the development of more efficient research approaches.

The **Social Care (Local Sufficiency of Supply) and Identification of Carers Bill** is a Private Member's Bill which has strong cross party support. It makes several key provisions which would help support the draft Care and Support Bill. If successful it would place a duty as follows: On local authorities to:

- Provide sufficiency of supply of social care services.
- Ensure sufficiency of supply of social care services for disabled people and carers who wish to work or go into education; and
- On NHS bodies to identify carers
- On schools to identify young carers
- On further and higher education establishments to identify young carers

The duty to identify carers would be invaluable in raising the profile of carers' needs and could be a powerful tool in bringing carers into the mainstream and helping to ensure that carers really are everybody's business. The requirement to provide a sufficiency of supply recognises that carers and people with disabilities have the right to expect appropriate services to be available to support them in returning to or maintaining their employment in much the same way that local authorities have a role to play in ensuring appropriate provision of childcare to enable parents to work if they wish to.





Health and Social Care Act (2012)

This Act will introduce comprehensive and far-reaching changes in the way in which the NHS is organised. It will abolish the current structures for commissioning and delivering health services and replace them with new clinically-led commissioning groups in which GPs will play a leading role. Carers are not directly affected by this Act but may be indirectly affected by any resulting changes in the way in which services are delivered to the person that they care for. Carers may indirectly benefit from the emphasis within the Act for commissioning intentions to be informed by those who use them and their carers.

Putting People First

Putting People First sets out the government's plans to reform adult social care. It defines these achievements as: '... a mainstream system focused on prevention, early intervention, enablement and high quality personally tailored services'. Key to its success will be for each individual to have 'maximum choice and control over the services they receive.'

Putting People First confirms that carers as well as the individuals they care for are integral to the success of the core values of personalisation '...real change will only be achieved through the participation of users and carers at every stage.

A Vision for Adult Social Care: Capable communities and active citizens (2010)

This builds on the principles of Putting People First and sets out the key priorities that need to be achieved in order that the visions set become a reality. In particular the document focuses on councils providing "personal budgets, preferably as direct payments, to everyone eligible within the next two years". In particular, it states the need to provide more carers with a direct payment to purchase breaks from caring over the next few years. In addition, it highlights the need for society and communities to take responsibility for social care as well as the state; "communities and wider civil society must be free to run innovative local schemes and build local networks of support"

The vision for adult social care sets out key principles of social care reform including;

Prevention; individuals maintaining independence for as long as possible will contribute to this.

Personalisation: people taking control of their own care and resultant services and support, where personal budget are key to its success

Partnership: this should be between individuals, communities, voluntary and private sector, NHS and Councils

Plurality: broadening of the market in terms of service provision will enable it to react well to the diversity of individual needs

Protection: individuals being safeguarded from abuse and neglect

Productivity: local accountability driving up improvements, with agreed and published quality outcomes helping to achieve this

People: the importance of a skilled workforce that is capable of leading this change. The re-design of carers' services needs to be viewed within the context of the vision and principles laid out above. The vision sets targets and challenges for local authorities and others to make the changes required to reform adult social care, with carers being key agents within this





change who need to be supported in order to contribute as fully as possible within society and within the social care economy.

The National Strategy for Carers – Carers at the heart of 21st century families and communities 2008.

The National Strategy for Carers, *Carers at the heart of 21st century families and communities: A caring system on your side.*' (June 2008) has five key objectives stating that carers should be:

- Respected as expert partners in care and will have access to the integrated and personalised services they need to support them in their caring role
- Able to have a life of their own alongside their caring role
- Supported so that they are not forced info financial hardship by their caring role
- Supported to stay mentally and physically well and treated with dignity
- Children and young people need to learn, develop and thrive, to enjoy positive childhoods and to achieve against all the Every Child Matters outcomes, while protecting them from inappropriate caring.

The Strategy sets out the government's commitment to services for carers and acknowledges the current difficulties many carers experience in accessing services from health and social care. This Strategy was updated by the Coalition Government in **Recognised**, **valued and supported**: **Next steps for the carers strategy (2010)** in which four priority areas were identified for action over the next four years. These priorities relate back to the outcomes that the Government is seeking to achieve:

- Priority 1 "Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages" relates most closely to the **first outcome**.
- Priority 2 "Enabling those with caring responsibilities to fulfil their educational and employment potential" relates most closely to the **third** and **fifth** outcomes.
- Priority 3 "Personalised support both for carers and those they support, enabling them to have a family and community life" relates most closely to the **second outcome**.
- Priority 4 "Supporting carers to remain mentally and physically well" relates directly to the **fourth outcome**.

Young Carers, parents and their families – Key principles of practice

In 2008 the Children's Society published 'Young carers, parents and families: key principles of practice⁴⁵. These principles are intended to be used alongside legislation and guidance already in place to enable agencies to respond to the recommendations of national policy, which affects young carers and their families. Using these key Principles of Practice will help ensure the best use of resources and promote whole family working.

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The six key principles are detailed below:

- Children's welfare should be promoted and safeguarded by working towards the prevention of children undertaking inappropriate care of any family member
- The key to change is the development of a whole family approach and for all agencies to work together, including children and adult services, to offer co-ordinated assessments and services to the child and the whole family
- Young carers and their families are the experts on their own lives and as such must be fully involved in the development and the delivery of services
- Young carers will have the same access to education and career choices as their peers
- It is essential to continue to raise awareness of young carers and to support and influence change effectively. Work with young carers and their families must be monitored and evaluated regularly
- Local young carer projects and other targeted services who work with young carers should be available to provide safe, quality support to those children who continue to be affected by any caring role within the family.

Currently, there are three main pieces of legislation that define statutory duties in relation to the assessment and support of carers. These are:

- The Carers Recognition & Disabled Services Act 1995
- The Carers and Disabled Children Act 2000
- The Carers (Equal Opportunities) Act 2004

Solicitor, Luke Clements summaries these in his 3rd edition of *Carers and their Rights in Relation to the Law* and underlines that local authorities have a duty to assess carers who provide or intend to provide a substantial amount of care on a regular basis and have the power to provide services to carers following an assessment. Clements states that the importance of the assessment process in gauging the impact on a carers ability to maintain 'daily routines' such as family relationships, employment, training and leisure commitments are a core requisite of any good assessment process.

The Equalities Act 2010

The Equalities Act 2010, for the first time, has recognised the role of carers and states that:

If you're looking after someone who is elderly or disabled, the law will protect you against direct discrimination or harassment because of your caring responsibilities. This is because you're counted as being 'associated' with someone who is protected by the law because of their age or disability. You're already protected from discrimination and harassment if they happen at work, but the new law will also protect you, if you are caring for a disabled person:

- when you shop for goods
- when you ask for services
- when you get services
- when you use facilities like public transport.

This is an important step in ensuring that carers' basic human rights are protected. Incorporating carers into the equalities law provides a platform for people who use services and their families to live as equal citizens.





Supporting People to Live and Die Well – a framework for social care at the end of life

Published in 2010 this report is the work of an advisory group of leaders in social care coordinated by the National End of Life Care Programme (NEoLCP). It maps out how social care commissioners and providers, together with those involved in training and education, can boost social care's role in end of life care for individuals and their families by:

- Offering training and support to the social care workforce from domiciliary care workers to social workers and their managers –to recognise the skills they already have and to develop new ones
- Consider end of life care within the current changes to commissioning and delivery of social care
- Embedding end of life care within the wider education and training changes currently taking place in social work and future development s in training and skills for the wider social workforce
- Incorporating end of life care within the personalisation and re-ablement agendas where there
 are significant opportunities for improving the experience of people approaching the end of
 their lives and the eir carers
- Strengthening palliative care social work in specialist settings and as an educational and supportive resource in mainstream services
- Achieving greater integration across all care and support services, particularly between social and health care
- Ensuring a robust evidence base to support the ongoing development of good social care practice in end of life care.





Appendix 3: Expenditure on support for carers

The Carers Special Grant from central Government was discontinued in 2009/10. Current funding for services to support carers is provided from within the overall County Council budget and through targeted funding from Warwickshire NHS Primary Care Trust.

Previously characterised by large block contracts for carers services the Carers Budget is developing a different profile to ensure that funding is allocated to where it can be used to facilitate personalisation and greater flexibility. This means moving away from block contracts to an increasing use of commissioning frameworks which enable frontline staff, customers and carers to purchase services that are tailored to their needs and which work well with personal budgets.

The following table provides an indication of how carers were supported in 2011/12 and some of the costs associated with that support. Using the measure NI 135 which calculates support to carers as a percentage of the service delivered to customers we know that 4071 carers received a carers' service, break or advice/information in the year following a carer's assessment or review.

The following table does not include the cost of providing the assessment service or the commissioning of support services.

Jointly Funded Support for Carers in Warwickshire

Following the refresh of the National Carers Strategy the Government identified a sum of £400 million nationally to be made available from 2011-15 through the NHS specifically for the purpose of providing support and breaks for carers.

The NHS Operating Framework for 2012/13 NHS requires PCT clusters to agree policies, plans and budgets with local authorities and voluntary groups to support carers, where possible using direct payments or personal budgets, and that these plans should be in line with the Carers Strategy.

In 2011/12 NHS Warwickshire transferred funding of £637,000 through a S256 agreement to Warwickshire County Council for support for carers. This was used to provide breaks for carers through the Home Care Framework and residential respite contracts and the following table provides a summary of provision resourced using that funding. For 2012/13 NHS Warwickshire will transfer a further £500,000 through a S256 agreement to Warwickshire County Council to continue funding and supporting carers.

In addition Warwickshire Primary Care Trust contributed £191,500 funding to services within the third sector during 2011/12 specifically to support carers and provide respite breaks.





The following table identifies the funding of services providing support to carers in 2011/12

Support	2011/12	No. of people	Service
	£*	receiving a service	Delivered
Replacement Care - Short	£2,425,700**	229	27,576 hours
Breaks - Residential		567	16,194 nights
Respite			
Day care	£ 192,200	212	
Homecare	£1,904,700	745	
Direct Payments:			
One-off	£ 33,900	95	
Ongoing	£1,559,300	290	
Carer Support	£ 535,000	4,500 Adult carers	
Services (Adult		830 Young carers	
and Young			
Carers)***			

^{*} Figures rounded







^{**} Includes £637,000 transferred from NHS through Section 256 agreement for support to carers

^{***} Includes a contribution from the NHS Warwickshire Primary Care Trust

Appendix 4: Current services supporting priorities

Current services supporting Priority 1 and identified gaps in provision

Supporting early self-identification and involvement in local care planning and individual care planning.

Service	Who provides it and how?
Information Services	
Fact sheets on specific condition	Guideposts Carers Support Service
 Signposting to specialist information 	
 Basic benefits advice and signposting to specialist information 	
Quarterly newsletter	
Support groups	
 Quarterly newsletter for carers of adults with Learning Disabilities 	Learning Disabilities Partnership Board
 Quarterly newsletter written by parents and carers caring for a child or young person with a disability 	Parent and Carer Steering Group - Integrated Disability Service
 Information about support for Young Carers for parents/carers, schools, Police, Social Care Services for adults and children 	Carers Support Service – Warwickshire Young Carers Project
Carer Awareness & and Recognition	
This tool is targeted at frontline staff to encourage them to consider how they might be able to assist carers by informing staff about the caring role and	Carer Aware eLearning tool, Warwickshire County Council – available to WCC staff and free access on internet for other agencies







enabling them to signpost carers appropriately.	
Cultural Training for social care assessment and reviewing staff Police, Social Care Services for adults and children	Commissioned by Warwickshire County Council for frontline staff in social care teams and Customer Service Centre
Working with schools,	Carers Support Service – Warwickshire Young Carers Project
Involvement of carers in local care planning and individual care planning	
Carers engaged in commissioning processes	Warwickshire County Council - Transformation Assembly. A register of carers who work in partnership with WCC.
Carers involved in assessment & planning process	Warwickshire County Council – Social Care Self Directed Support (SDS) process involves carer in the assessment of cared for and development of support plan.
Parent/Carers involved in decision making, commissioning and service direction	Integrated Disability Service – Parent & Carer Steering Group, Countywide Parent and Carer Forum

Identified gaps in provision

- Good quality information about caring for conditions/illnesses easily accessible within health, social care and community settings
- Good quality information about available services and how to access them.
- Information for carers of people approaching the end of their lives
- Clear links to housing related support







Current services supporting Priority 2 and identified gaps in provision

Enabling carers to fulfill their educational and employment potential

Current Services	Who provides it and how?
Carers Assessment identifies carer's wish to work/pursue education and addresses this within carer's support plan.	Social Care Services – utilising Direct Payment to fund educational course
Customers Assessment identifies where replacement care is required to support carer's employment/education	Social Care Services – addresses need for replacement care within customer's support plan.
Replacement care	Social Care Services – utilising Homecare Framework, other services, Personal Budgets, Direct Payments.
Young Carers Service	Carers Support Service – Warwickshire Young Carers Project - liaison with schools/colleges/employers to provide support/awareness raising

Identified gaps in provision

 A wide range of affordable care replacement options to enable carers to access education and employment opportunities







Current services supporting Priority 3 and identified gaps in provision

Personalised support for carers and those receiving care, enabling them to have a family and community life

Current Services		Who provides it and how?
Carers' Assessm for support to ma family/community		Social Care Services – utilising Direct payments to provide appropriate support eg laptop to aid communication with family/friends
need for carer to	essment – identifies take breaks to and community life	Social Care Services – incorporates replacement care within customer's support plan to enable care to take a break to maintain family/community life
carers to take a k	ement care enabling break from their also provision of acement care to avoid	Homecare Framework – this is a structure with access to a wide range of service providers able to put care staff in to the customer's home to replace the informal carer or take the customer out, enabling the carer to take a break.
Residential respi	te	A range of specialist providers able to offer personalised care and support in a residential setting, enabling the informal carer to take a break from the caring role.
hospice and outp	ve care inpatient day patient service. Also s in their own home g.	Myton Hospice - offering a whole familiy approach to caring support and training, emergency support, information and 1:1 support for people with a terminal diagnosis and their carers.
Day Hospice, Ho Lymphoedema a Support Services	nd Bereavement	Mary Ann Evans Hospice – providing emotional support and information and 1:1 support for people with a terminal diagnosis and their carers.
Day Hospice faci Home	ility, Hospice at	The Shakespeare Hospice - providing care for patients with life limiting illnesses and support for families and carers. Services include emergency support, information and 1:1 support
families caring fo	ools, settings and or a child/young stic spectrum disorder	Autism Team includes social workers, teachers, inclusion assistants and youth worker. Integrated Disability Service







Identified gaps in provision

- Better joined up services between health and adult and children's services, supporting children and adults with Autistic Spectrum Disorder.
- Future planning for cared for to enable carers to feel confident about the future of the person they care for.
- Future planning for carers to enable carers to prepare for when their caring role may end.
- Wider range of support options within the community.

Current services supporting Priority 4 and identified gaps in provision

Supporting carers to remain physically and mentally well

Service	Who provides it and how?
Carers' Assessment – identifies need for support to promote health and wellbeing	Social Care Services - utilising Direct Payments to provide appropriate support to achieve desired outcome eg gym membership, referral to counselling services, life coaching
Customers' Assessment – identifies – need for carer to take breaks to maintain health and wellbeing	Social Care Services -incorporates replacement care within customer's support plan to enable carer to take up gym membership/counselling, etc
Carers' Support Service	Guideposts Carers Support Service – advice and information Carers Support Service – Warwickshire Young Carers Project - advice and information
 Training for carers: to relieve anxiety, provide practical caring skills, moving and handling, on caring for specific conditions eg dementia, autism, etc Training for young carers to help manage caring role, how to seek help, etc 	Guideposts Carers Support Service – direct provision of training eg caring with confidence and via training delivered by specialist providers. Carers Support Service – Warwickshire Young Carers Project - direct provision by Project staff
Emotional Support, 1 to 1 and group support	Guideposts Carers Support Service – provided through staff by phone, home visits and groups and peer support from other carers







Emotional Support, 1 to 1 and group support	Carers Support Service – Warwickshire Young Carers Project - provided by Project staff by phone, face to face and within group setting
Training for parents/carers of newly diagnosed children : Early bird and APT	Integrated Disability Service – provided by staff on 1:1 and group basis

Identified gaps in provision

- Regular health checks for carers
- Countywide training for carers in managing care for people with specific conditions/illnesses
- Support for cared for provided to enable carers to attend support groups where no other care is available







Appendix 5: Making it happen and knowing when we have

Framework for monitoring and evaluating delivery against Carers Strategy Refresh priorities

Adult Social Care Outcomes Framework – (ASCOF)

There are four domains within the ASCOF, three of which carry a carer-related outcome measure:

1 Enhancing quality of life for people with care and support needs

Carer -related outcome measure: Carers can balance their caring roles and maintain their desired quality of life

- 2 Delaying and reducing the need for care and support:
 - Carer -related outcome measure: Earlier diagnosis, intervention & reablement mean that people and their carers are less dependent on intensive services
- 3 Ensuring that people have a positive experience of care and support.
 - Carer -related outcome measure: Carers feel that they are respected as equal partners throughout the care process
- 4 Safeguarding adults whose circumstances make them vulnerable and protecting from avoidable harm

NHS Operating Framework - Carers

The NHS Operating Framework 2012/13 requires that PCT clusters need to agree policies, plans and budgets with local authorities and voluntary groups to support carers, where possible using direct payments or personal budgets. For 2012/13 this means plans should be in line with the Carers Strategy and be explicitly agreed and signed off by both local authorities and PCT clusters and identify the financial contribution made to support carers by both local authorities and PCT clusters and that any transfer of funds from the NHS to local authorities is through a section 256 agreement. This information is included in Section 3 of this Strategy.

Coventry and Warwickshire Partnership Trust (CWPT) Carers Monitoring

Carers Key Performance Indicators (KPI's) are included within the performance dashboard for CWPT and are as follows:

Performance Indicator	Threshold	Method of Measurement	Frequency of reporting
Implement the carers element of the 'Equal Partners Strategy'.	Update on progress by end of Q1 with plans to fully implement with timescales.	Carers Support Report to illustrate how the Provider has implemented the strategy.	Bi-annual







Number and % of clients in receipt of services who have their main carer identified and recorded in their care plan with contact details.	100%	Data reported quarterly. Number and %, month actual and year to date.	Quarterly
Number and % of carers that have been identified who have been offered a carers assessment, where appropriate, and where accepted the assessment has been undertaken and recorded in the patients care plan.	100%	Data reported quarterly. Number and %, month actual and year to date.	Quarterly
All individuals at risk of falling and their carers will receive a brief intervention including information orally and in writing about what measures they can take to prevent further falls	95% compliance for patients identified as at risk of further falls	Quarterly progress/audit report to CQR	Quarterly

Warwickshire Corporate Business Plan 2012-13

The delivery of the Carers Strategy Refresh action plan will also contribute to the achievement of Warwickshire County Council's Corporate Business Plan in the following areas:

Warwickshire's residents have more choice & control

The proportion of those using social care who have control over their daily life

Warwickshire's residents have more choice & control

The proportion of people who use services and carers who find it easy to find information about support







Section Four

Delivery Plan

The following tables provide a summary of all the actions from each priority heading with associated outcomes and performance measure.





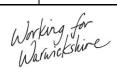


Priority 1 - Supporting early self-identification and involvement in local care planning and individual care support planning.

Outcome	Actions	Measures	Lead/Reporting Officer
Carers are identified at an early stage in their caring role and provided with, or signposted accurately to, sources of information and support.	 Promote Carer Aware eLearning tool on intranet to frontline staff across all Directorates of County Council to raise awareness and early identification of carers and facilitate signposting to appropriate information. Promote Carer Aware eLearning tool on internet to partner organisations in all sectors. 	No. of WCC staff completing Carer Aware e Learning Tool on intranet. No. of uses of WCC internet Carer Aware e learning Tool.	Learning & Development WCC
Carers have easy access to information and advice about benefits, services and practical support for their caring role.	Ensure that carers information needs are met by: Improving information availability and utility for carers, enabling them to access information and advice relating to services and support for customers and carers.	Carers Survey	Carers Lead Officer
	 Addressing the requirements of the draft Care and Support Bill for a comprehensive information service. 		
	Integrated working across local health and social care strategies and associated web/helpline -based information services and effective linking to national sources of information and support.		
	 Providing multi-accessible formats ie not only web- based. 		
	Achieving integrated working across health and social care to ensure carers are		



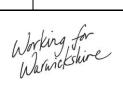




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	 accurately signposted to sources of specialist information ie specific conditions, financial advice, brokerage, end of life care, etc Using language and terminology that promotes accessibility ie not "carer" 		
Carers are able to access practical information/ support for their caring role	All local health and social care strategies to incorporate carers' requirements for good quality practical information about caring for conditions/illnesses and make this information available within appropriate health, social care and community settings including GP practices, hospitals and children's centres and via web portals.	Carers Survey	Head of Strategic Commissioning
Carers looking after people who are approaching the end of their lives are identified at the earliest opportunity and given appropriate support and information at each stage of the caring role	 Scoping for introduction of "indicator" on Carefirst screen to denote terminal diagnosis and alert practitioner to offer appropriate support and signposting for carer. Training for social care staff to inform and support their interaction with carers of people with a terminal diagnosis. 	No. of End of Life carers identified.	IMT
Carers have a clear understanding of reablement, its benefits and their own role in supporting its objectives	Early identification of carers at hospital discharge and onset of reablement service and provision of information to carers about reablement during the perod that their cared for person is using this service.	No. of carers identified and signposted/referred to support	Hospital discharge Teams Reablement Teams
Carers are engaged and have a voice	Scope greater collaboration across social care and health engagement programmes to maximise the outcomes from consultative and engagement activities and reduce duplication	No. of collaborative engagement activities	Carer & Customer First Team



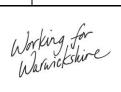




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	Carers feel consulted and involved in individual care support planning.	Frontline staff ensure carers are involved in individual care support planning and the outcomes identified.	Monitor carers satisfaction with involvement No. staff trained in inclusive support planning	New Care First measure awaited
	Young Carers are able to thrive and achieve their educational goals	Work collaboratively with schools and colleges to facilitate early identification of Young Carers and signposting to appropriate support.	No. of young carers identified by schools and colleges No. of young carers referred to social care/health services	Young Carers Project
	Carers are identified at an early stage and given appropriate information and support.	Carers assessments offered by health practitioners within health settings ensuring that carers receive information, support and signposting at the earliest possible stage enabling them protect their health and wellbeing.	No. of health practitioners trained to offer carer assessments No. of carers assessments carried out by health practitioners	Carers Lead Officer
	Adult and young carers within families/households are identified and given appropriate support.	 A Whole Family Approach is applied to assessments of children and adults to identify carers and linked to work underway to implement the Memorandum of Understanding between Adult and Children's Social Care Services. Review of practices within adult and children's teams to ensure consistency of approach in supporting carers. 	Revised protocol in place. Frontline staff in Adult and Children's Socilal Care Services trained in revised protocol	TBC
	Carers are able to access information about local services	Promotion of the Resource Directory to carers and self funders.	Increased use of Resource Directory	TBC







Carers from Black and Minority Ethnic communities are able to access information about available support	Carers Support Service outreach activity to BME communities and employers to promote awareness of support	Increase in BME carers taking up services Increase in BME users of Carers Support Service	Carefirst Guideposts Carers Support Service
Carefirst carer data profile improved	Review carer data entry requirements and recording practice to ensure profile of carers is updated to inform commissioning decision-making.	BME data for carers improved	IMT/Business Intelligence

Priority 2 - Enabling carers to fulfil their educational and employment potential – ensuring that carers are not financially disadvantaged and that children will be thriving, protected from inappropriate caring roles.

Outcome	Actions	Measures	Lead/Reporting Officer
Carers are aware of their right to request flexible working	Information about combining work and caring available to practitioners and carers on WCC carers web pages together with signposting to specialist information and advice.	No. of staff/teams trained No. of employed carers maintaining employment?	Learning & Development New Care First measure awaited
Carers at risk of giving up employment identified at	 Frontline staff in social care and Customer Service Centre Carer receive awareness training regarding 		Carers Lead Officer



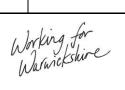




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earliest opportunity	 employment right to request flexible working and information about combining work and caring. Carers at risk of giving up employment prioritised for assessment. 		
Carers are able to access a range of support options to help them maintain their education/ employment	 Use of Homecare Framework to source replacement care. Use of assistive technologies and telecare/telehealth support to enable carers to maintain education/employment. 	Replacement care used to support education/employment No. of instances where assistive technology, etc used to support education/employment	New Care First measure awaited
Young carers thriving and achieving at school and protected from inappropriate levels of caring	Establish clear pathway to implement the memorandum of agreement between Adult and Children's Social Care Services to ensure that young carers are identified and supported from an early stage	Academic achievements of young carers compared with general population	Learning & Achievement/To Be Confirmed
Young Carers are able to thrive and achieve their educational goals	Work with schools to ensure that each school has a designated staff member for young carers who will play a crucial role in improving outcomes for this group of vulnerable children	No. of schools with designated staff member for young carers	Learning & Achievemen To Be Confirmed t/
Young adult carers (18-24) are supported in achieving academic and employment success	Work with colleges, local universities, private sector and voluntary organisations to give consideration to the specific needs of young carers and to provide opportunities to develop skills and access to employment.	% of young adult carers in education or employment	TBC
Carers supported into work	 Carers with learning disabilities supported into work Scope expansion of service provided by WEST 	No. of carers supported into work or training	Service Manager, Strategic Commissioning







	(Warwickshire Employment Support Team) to include support for all carers .		
Carers have access to educational courses	Promote Adult Community Learning courses to carers via social care teams and carers support services.	No. of carers accessing ACL courses	Carers Lead

Carers Strategy Refresh 2012-14

Priority 3 – Personalised support for carers and those receiving care, enabling them to have a family and community life

Outcome	Actions	Measures	Lead/Reporting Officer
Carers have access to information about clinical and social care pathways and experience seamless services in health and social care	Local strategies to identify clear information about clinical and social care pathways for and ensure access to this information for carers.	Each Strategy to include clinical & social care pathways Each Strategy to identify where and how information will be made available and how it can be integrated in to existing carer information services.	Service Redesign Officers/Clinical leads
Carers are able to access a range of appropriate and affordable replacement care.	 Improve range and availability of replacement care options by: Requirement for all local Strategies to consider replacement care options for carers. 		
	 Review of replacement care provision to inform commissioning intentions. Consideration of 		
	commissioning to stimulate		





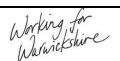


	development of community/volunteer-based support options.		
Carers feel supported in planning for the future care of the person they look after	Future planning for the cared for – to develop a template for use in helping carers to plan for, and feel more confident about, the future of the person they care for through consideration of financial, accommodation and legal issues which may need to be addressed to provide security for the cared for person and peace of mind for the carer.		Carers Lead Officer
Carer feel supported in planning for their own future	Future planning for carers - develop a template for use in helping carers to prepare and plan for when their caring role may end. This may need to address bereavement support, training/education and social/community support.		Carers Lead Officer
Carers are able to experience and enjoy a life outside of their caring role	Roll out cultural and business process training for frontline staff on new Customer and Carer assessments. The new Carers Assessment to focus on the carer's life outside of caring and their health and wellbeing.		Learning & Development
Carers experience seamless service transfer at transition	Apply the Whole Family Approach to transition arrangements ensuring that the transfer from Children's to Adult services provides carers with clear information and care pathway.	Carers outcomes met	Transition teams

Priority 4 – Supporting carers to remain physically and mentally well







Outcome	Actions	Measures	Lead/Reporting Officer
Carers are mentally and physically well	Work with individual GPs and the Clinical Commissioning Groups to facilitate regular health checks for carers and access to appropriate counselling support.		Carer Lead Officer
Carers trained in practical management of caring role	Countywide training for carers in managing care for people with specific conditions/illnesses such as Autistic Spectrum Disorder, Dementia, Mental Illness, etc. All strategies need to consider practical training for informal carers within their proposals for workforce development and training.		Service Redesign Officers/Clinical leads
Carers are able to obtain replacement care to enable them to access support for themselves	Customer assessments include consideration of need to for replacement care to enable carer to access own support eg 1to1 or group support for carers.	Carer outcomes met	Carers Lead Officer
Young Carers health and wellbeing Is protected.	Work with school nurses to provide health checks for young carers	No. of young carers attending health checks	Young Carers Project/Learning & Achievement (To Be Confirmed)
Carers of people who are at the end of their lives receive timely and appropriate support	 Ensure that appropriate End of Life requirements are built into contract specifications / quality requirements. Provision of training on Gold Standard Framework and Liverpool Care Pathways for residential care / home care providers. 	Contracts include End of Life requirements Training provided for social care and	End of Life Social Care Lead/ Learning & Development/Service Redesign Officers
	Training for front line Social	independent sector care	







Carers are mentally and physically well	Care Services staff on providing appropriate, timely and sensitive support to carers following a terminal diagnosis. Carer's Assessments will offer the opportunity to focus on the carer's health and wellbeing with Direct Payments being offered creatively to support related outcomes eg through gym membership, fitness classes, etc.	staff.	Social Care ServicesTeam Managers
Carers are mentally and physically well	Provision of county-wide support offering emotional, 1 to 1, peer and group support, relaxation and coping strategies, and practical management of the caring role eg moving and handling.	Contract monitoring requirements	Carers Support services
Young Carers are able to thrive and achieve their educational goals	Ensure that schools and colleges are aware of their role in offering appropriate interventions to young carers in collaboration with partner agencies such as Young Carers Project, Children's Services, etc.		Integrated Disability Services





