Caring Together

The Carers Strategy for Scotland 2010 - 2015

26 July 2010

COSLA

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SCOTTISH GOVERNMENT

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Please contact 0131 244 4040.

ISBN: 978-0-7559-9484-7

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St Andrew's House
Edinburgh
EH1 3DG

Produced for the Scottish Government by APS Group Scotland
DPPAS10110 (07/10)

Published by the Scottish Government, July, 2010

This document is also available on the Scottish Governments website:
www.scotland.gov.uk

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Foreword

The Scottish Government and COSLA are determined to ensure that carers are supported to manage their caring responsibilities with confidence and in good health, and to have a life of their own outside of caring.

We are pleased to have worked together with a range of interests, including Health Boards, the national carer organisations and carers in developing this strategy. It will build on the support already in place and take forward the recommendations of the landmark report, *Care 21: The Future of Unpaid Care in Scotland*.

We recognise carers as equal partners in the delivery of care in Scotland and fully acknowledge carers' expertise, knowledge and the quality of care they give. With appropriate support, especially support delivered early to prevent crisis, caring need not have an adverse impact on carers.

Caring Together sets out 10 key actions to improve support to carers over the next five years. The focus is on improved identification of carers, assessment, information and advice, health and well-being, carer support, participation and partnership.

In support of this agenda, the Scottish Government is pleased to announce an investment of a further £1 million in 2010-11 to voluntary sector organisations to provide more innovative short breaks provision in Scotland.

The strategy sits within a wider context and reform agenda, with carers at the heart of this agenda. In order to achieve lasting change both for carers and the people they care for, we need to drive forward a range of policy developments, such as action to tackle health inequalities and household income. We need to do more to shift resources from institutional care to care at home, including support for carers. The Reshaping Care for Older People Strategic Delivery Plan, which is in preparation, will articulate the extent of the shift in resources within the system.

We are also pleased to have produced *Getting it Right for Young Carers,* which we believe will result in better outcomes for young carers. To the best of our knowledge, it is the first ever national young carers' strategy in Europe. We recognise that many young people can benefit from providing care to a relative or friend affected by illness, disability or substance misuse. However, we are committed to ensuring that young carers are relieved of inappropriate caring roles and are supported to be children and young people first and foremost.

We are taking important steps to improve young carer identification and support within schools, colleges and the health service. The strategy also endorses an approach which organises services around the child or young person so that all the needs of the child or young person will be identified and

addressed, including the impact of caring on their health, well-being and education.

In support of this agenda, the Scottish Government is pleased to announce funding of £150,000 for a fourth Young Carers Festival in 2011. This will bring together young carers from all over Scotland to socialise, have a break from caring and let them meet other young carers. Young carers will be able to tell national and local decision-makers what difference this strategy is making (or not) to their lives one year on from publication.

There is an important point relevant to both *Caring Together* and *Getting it Right for Young Carers*. The Scottish Government gave Health Boards £9 million for Carer Information Strategies in the last three years, with £5 million of this allocated this year. Until the Spending Review is concluded, the Scottish Government cannot confirm the resource of £5 million from April 2011 onwards. However, we see this as a priority for that review. Also, completion of some of the other actions in this strategy will depend on the outcome of the review.

We believe that *Caring Together* and *Getting it Right for Young Carers* represent an important step forward in creating a framework for action. Together, and through implementation of this strategy over the next five years, we will improve the lives of carers and young carers.

Shona Robison
Minister for Public Health and Sport

Councillor Douglas Yates
COSLA Spokesperson for Health and Wellbeing

Adam Ingram
Minister for Children and Early Years

Councillor Isabel Hutton
COSLA Spokesperson on Education, Children and Young People

This is a guide to the design features within the strategy:

ACTION POINTS

"Quotes from carers to illustrate points made."

References to good practice –examples of good practice (and carers' stories) are set out in a separate document accompanying this strategy.

Points for emphasis, including useful information which does not form an Action Point because the action is already underway and is not new.

Young carers – reference to young carers within the carers part of the strategy.

The text or narrative.

EXECUTIVE SUMMARY

Headline Message

Carers are equal partners in the planning and delivery of care and support. There is a strong case based on human rights, economic, efficiency and quality of care grounds for supporting carers. Without the valuable contribution of Scotland's carers, the health and social care system would not be sustained. Activity should focus on identifying, assessing and supporting carers in a personalised and outcome-focused way and on a consistent and uniform basis.

The Government's Headline Actions

The following are the headline actions in this strategy to help improve outcomes for carers:

1. We acknowledge the immense contribution carers make to society and the need for appropriate support. **We will develop a Carers Rights Charter**, consolidating existing legal rights and setting out key principles for carer support both now and in the future.

2. **We will put in place measures to help professionals in the health and social care workforce identify carers.** Carer identification opens the door to a carer's assessment and to the provision of support. There will be a strong emphasis on workforce training as members of the workforce who are 'carer-aware' have a big role to play.

3. **We will take steps to improve the uptake and quality of carers assessments/carer support plans.** This will be achieved through workforce training and widely-disseminated guidance as well as by inclusion of the role of assessments in the forthcoming NHS *inform*

carers information zone. Carers centres will continue their vital work in supporting this process.

4. **We will improve the provision of information and advice to carers** through various means including workforce training and our support for NHS *inform*.

5. **We will ensure carer representation on Community Health Partnerships.** Carers will be central to the planning, shaping and delivery of services for the people with care needs and in relation to support for themselves.

6. As carers can suffer poor health directly as a result of caring, carer health and well-being is vitally important. **We will produce a bespoke resource on issues relating to stress and caring** to complement the successful *Steps for Stress*. **We will continue to work with the Royal College of General Practitioners Scotland and the national carer organisations on carer identification and support**, including promoting good health. **We will ensure that carers aged 40-64 have access to health checks** under plans to target groups of people, including carers, who may not live in the most deprived areas – those eligible people in the most deprived areas will already have access to health checks under the Keep Well initiative.

7. Carer training promotes carer confidence and enables carers to care for longer. **We will invest £281,000 in carer (and workforce) training this year through a grant to the national carer organisations**. We will work with NHS Boards to ensure a 'training offer' may be made to carers in greatest need, contingent on the outcome of the next Spending Review.

8. The provision of short breaks or respite is hugely important to carers. We will work with a range of partners to promote the further development of flexible, personalised short breaks. Local authorities will continue to provide, and support access to, short breaks. **We will invest a further £1 million in 2010-11 to provide more innovative short breaks provision in Scotland to be delivered by the voluntary sector.**

9. It is important for carers to be able to remain in employment, when they want to, or to take up employment, learning or training opportunities. **We will encourage and promote carer-friendly employment practices.** Skills Development Scotland will be working with the national carer organisations to help promote learning and other career opportunities.

10. There is a clear need for better strategic planning and collaborative working between health and social care services to ensure the delivery of co-ordinated services and supports. **We will work to ensure this happens so that carers do not have to negotiate the boundaries of different health and care services.**

Appendix 1 sets out the membership of the Carers Strategy Steering Group which helped inform strategy development. **Appendix 2** sets out the membership of the Carers Reference Group, comprising carers from different parts of Scotland and with different caring experiences, which also helped inform strategy development.

Chapter 1: Action Points and Implementation

Chapter 1 sets out the arrangements for implementation of this strategy. The consolidated list of Action Points is at **Appendix 3.**

Chapter 2: Introduction

Chapter 2 sets out the shared vision for unpaid carers (carers) in Scotland where carers are recognised and valued as equal partners in care; supported to manage their caring responsibilities; fully engaged in the planning and development of services; and not disadvantaged or discriminated against by virtue of caring. We set out a number of key outcomes linked to the vision.

Carers play a crucial role in the delivery of the health and social care system in Scotland. This role will become more important as a result of demographic and social changes. Carers need to be at the heart of a reformed health and social care system with a shift from residential, institutional and crisis care to community care, early intervention and preventative care. We make clear that in making radical changes to the health and social care system, carers should not be burdened, but supported and sustained in their caring role.

We set out the economic and efficiency arguments for supporting carers, whilst recognising the fundamental human rights and equalities perspective. We make clear that **much more needs to be done to achieve practical support on a consistent and uniform basis and in a way which enables carers to have a quality life of their own outside of their caring responsibilities.**

Appendix 4 sets out resources committed by the Scottish Government to date for support to carers. There is a focus on the challenging economic climate. There is also a clear statement that despite the extreme pressures on public finances, **local authorities and Health Boards will commit to delivering incremental improvements to support for carers. This recognises that the demand on current statutory health and social care provision is unsustainable without changes in the pattern of service delivery.**

This chapter sets out the role of the Scottish Government, COSLA, local authorities, Health Boards, the national carer organisations and other partners in delivering the strategy.

We make clear that there will be a baseline position against which to measure progress over the next 5 years.

We outline our commitment to publish, at the same time as this strategy, good practice to show the innovation of local authorities, Health Boards, the Third Sector and private sector. We are also publishing a selection of 'carer stories' to show the wide range of caring experiences, both positive and negative.

We highlight the importance of the *Care 21 Report: The Future of Unpaid Care in Scotland*, which contained 22 recommendations in relation to carers and young carers. We set out progress since the publication of Care 21 in **Appendix 5.**

Chapter 3: Profile of Carers

Chapter 3 summarises a range of data on the characteristics of carers, including age, gender, hours spent caring each week, whether working or not, and socio-economic background. **Appendix 6** sets out the number of identified carers by local authority area.

We discuss the difficulties of collecting data on Black and Minority Ethnic (BME) carers and state the action in hand to make progress on this front. We discuss the diversity of both the carer and cared-for population. **We make clear that support for carers needs to take account of the dynamics of the caring situation and to be tailored accordingly.** We acknowledge that there are groups of carers we know little about, such as carers with disabilities, gypsy travellers and refugees and that we should address this lack of knowledge.

Chapter 4: Prioritising Support to Carers

Chapter 4 focuses on the need for statutory and Third Sector organisations to prioritise support to carers in greatest need, according to local partnerships' own definitions of need, based on needs assessment work. Some caring situations will be more challenging than others but where caring responsibilities are minimal, plans should be put in place to prepare for any escalation in the demands on the carer. An emphasis on preventative action and early intervention should be the default position rather than crises-led responses which happen after an escalation of the problems and issues. Small packages of cost-effective support delivered in a timely way are appropriate.

Chapter 5: Equalities

- Equality Groups
- Caring in remote and rural areas

In addition to the many references to equalities issues throughout the strategy, **Chapter 5** focuses on the need to fully recognise and implement in a meaningful way, and to further mainstream, equalities issues. Carers should not be discriminated against on the grounds of age, ethnicity, gender, disability, sexual orientation or religion. Therefore, efforts need to be made to identify and support carers who can sometimes be 'hard-to-reach.'

This chapter builds on the references throughout the strategy to the particular needs of carers in remote and rural areas, including accessibility of services for the cared-for person, the lack of easy-to-reach respite provision, the additional costs of caring in remote and rural areas, difficulties in delivering carer training and so on. We set out in **Appendix 7** the full range of Scottish Government policies designed to improve transportation in remote and rural areas. We will work with key partners to identify innovative solutions to help address some of the issues.

Chapter 6: Carers Rights

Chapter 6 makes clear our intention to develop a Carers Rights Charter which will consolidate in one place existing carers rights and set out key principles for the future. Subject to a Self-Directed Support Bill being introduced into Parliament, and receiving Royal Assent, there will be a further legal right for carers to receive direct payments if various criteria are met. We will promote the Equality Act 2010. We make clear that the delivery of all the Action Points in the strategy should drive forward support for carers over the next 5 years, and beyond.

Chapter 7: Carer Involvement in Planning, Shaping and Delivering Services and Support

Chapter 7 makes clear that services and support will only be planned and delivered effectively and efficiently if carer organisations and carers are fully involved at all stages. Since carers comprehensively outnumber the paid workforce, they should have a central role in planning, shaping and delivering services and support. The Scottish Government will ensure carer representation on Community Health Partnerships (CHPs). The

review of Public Partnership Forums will involve carer representatives. The Healthcare Quality Strategy for Scotland is also ensuring carer involvement in important issues regarding the quality of healthcare services. There should also be carer involvement in procurement processes.

Chapter 8: Identification of Carers

Chapter 8 sets out the most effective ways to identify carers and stresses the pivotal role of practitioners in the health and social care professions, who are trained in carers' issues. Carer self-identification is also important. Identification is the first step to having a carer's assessment and accessing support – enabling carers to be identified or to self-identify is therefore critical. To this end, we will continue to work with the Royal College of General Practitioners Scotland and the national carer organisations. NHS Boards need to continue to support carer identification beyond 2011, when current Carer Information Strategy funding comes to an end. We will work with Alcohol and Drugs Partnerships (ADPs) and the new Scottish Drugs Recovery Consortium (SDRC) to help identify and support carers of people with addictions and substance misuse problems. **Appendix 8** sets out a carer pathway from identification through to support.

Chapter 9: Carers Assessments (Carer Support Plans)

Chapter 9 sets out the range of actions to help improve the uptake of carers assessments/carer support plans, to enhance the quality of the assessments being undertaken and to provide more and better support following an assessment. There will be further work to ensure that the *Talking Points* approach to the undertaking of assessments is pursued rigorously. There is an emphasis on the need for practitioners to be fully trained in the carrying out of assessments and to acquire knowledge about services and support available locally. With the right focus, the assessment should lead to carers being signposted to appropriate support. Assessments must be revisited and reviewed to take account of changing circumstances and must take account of the wider needs of carers.

Chapter 10: Types of Support

Chapter 10 is a link chapter to the following chapters, which set out action to improve the planning and delivery of different types of support.

Chapter 11: Information and Advice

Chapter 11 sets out the importance of carers having access to up-to-date, good quality information and advice whenever they need it. The Carers Information Zone, to be launched later by NHS *inform,* will provide useful information and advice on-line. Information and advice will also continue to be provided by carers centres, Health Boards, GP practices, local authorities, condition-specific organisations and by others. We will scope the potential for a Scotland-wide carers helpline, and the options for providing it.

Chapter 12: Carer Health and Well-Being

Chapter 12 focuses on the mental, emotional and physical health of carers. Early identification of carers and the provision of support is the key to carer health and well-being. Carers centres play a major role in improving carers' overall health and well-being, as do other organisations. We will commission a bespoke resource for carers, building on Carers Scotland's health guide for carers to complement *Steps for Stress.* We want NHS Boards, CHPs and local authorities to ensure carers have access to training on moving and handling. Health checks will be provided to eligible carers. We will promote to carers the health benefits of the seasonal flu vaccine.

Chapter 13: Short Breaks (Respite)

Chapter 13 emphasises the importance of providing flexible, personalised short breaks provision to carers. Innovative solutions are required to help meet demand. Such solutions can focus on, for example, the use of volunteers to give carers a break, building community capacity, ensuring more flexible use of and access to universal provision such as playschemes for children with disabilities, more beds being available in care homes for respite in suitable circumstances and increasing the use of direct payments to purchase personalised respite. We will invest £1 million in 2010-11 to provide carers with short breaks.

Chapter 14: Training
- Carer training
- Workforce training

Chapter 14 makes clear that carers who receive training, if they need it, feel better supported in their caring role, and more confident. Whilst there is a great deal of carer training being undertaken by Health Boards, national carer organisations, local authorities and others, this needs to be consolidated and carried forward. The grant the Scottish Government has given to the NCOs in 2010-11 of £281,000 will be used to expand carer (and workforce) training. The NCOs will build on the good practice in training pilots the Scottish Government also funded – in Lothian, with BME communities and in rural areas. NHS Boards should continue to deliver carer training. Subject to the outcome of the Spending Review, we will work with NHS Boards so that they may make an offer of training to carers in greatest need.

Workforce training in carer awareness and carer support is essential. A well-informed, knowledgeable, trained and skilled health and social care workforce can help improve the lives of carers. NHS Education for Scotland (NES), with NHS Boards and the NCOs, will build on current work and identify training materials to be used within core induction, education and training curricula. NES will communicate to the relevant regulatory, professional and national bodies the crucial importance of workforce training. We will work with NHS Boards to ensure workforce training is carried forward. We will also work with the Scottish Social Services Council.

Chapter 15: Housing and Housing Support

Chapter 15 acknowledges that housing is an important element in enabling carers to support the person they care for to live independently, if possible, safely and with dignity in their own homes and communities. Housing must be suitable for changing needs. Under the Reshaping Care programme, five main outcomes have been identified for older people's housing. We need to develop more effective links between housing, social care and health policies, with carer involvement, and will work towards achieving this.

Chapter 16: Use of Assistive Technology - Telecare - Equipment and Adaptations

Chapter 16 covers both telecare and equipment and adaptations. Much has been achieved over the last few years to ensure the availability of telecare which benefits carers significantly, delivering good outcomes. We want to maximise the impact of telecare investment to ensure that the benefits and application of new technology for carers continues and develops.

We recognise the benefits of suitable equipment and the need for adaptations to be carried out efficiently and when required. There is a need to build on the existing work to ensure that carers have appropriate information on equipment and adaptations services and that they receive training on the use of equipment.

Chapter 17: Advocacy Support

Chapter 17 sets out the benefits of advocacy support to carers, especially those who are the most vulnerable. There are only three carer advocacy organisations in Scotland. Given this scarcity of provision, and the outcomes that can be achieved through advocacy, we urge local authorities, NHS Boards and other local partners to develop or expand carer advocacy services for those in greatest need.

Chapter 18: Employment and Skills

Chapter 18 is clear that people should not have to give up work to care and should not find difficulty accessing work. Carers should be supported in employment through carer-friendly policies and practices. Work provides carers with a sense of normality, a life outside of caring and is the key to addressing carer poverty, including maintaining pension rights. With changing demographics, many carers who want to work should be helped to do so, as there will be a shrinking working-age population. We will encourage and promote carer-friendly employment practices and Skills Development Scotland will help carers into training and employment. Carers should also be supported to enjoy lifelong learning opportunities to improve their own well-being.

Chapter 19: Tackling Poverty: Financial Inclusion

Chapter 19 focuses on the financial consequences of caring, the low take-up of benefits by carers and service users, fuel poverty and local authority charging policies for services and support. **Appendix 9** sets out the fuel poverty energy assistance package.

Increasingly, Community Planning Partnerships are enhancing mainstream services which address income maximisation, debt advice and financial capability. Carers centres, national carers organisations and others provide advice on benefits and income maximisation. Where voluntary services are located in GP practices to advise and support carers, there has been a take-up in benefits by carers.

We will pursue with the new UK Government the level of the Carer's Allowance and a review of financial support to carers. COSLA also provides guidance to local authorities on charging policies and is developing a benchmarking facility to facilitate consistent approaches in this regard.

1. ACTION POINTS AND IMPLEMENTATION

1.1 The Scottish Government and COSLA intend to ensure that the Action Points in this strategy are taken forward and will keep the strategy under review to be able to respond quickly to new policy, fiscal and resource developments. We will formally review this five-year strategy by August 2013. We will scope out the nature of this review later.

1.2 The consolidated list of Action Points is set out in **Appendix 3.** A detailed Implementation Plan will be further developed over the coming months.

1.3 The Scottish Government intends to establish an Implementation and Monitoring Group comprising a range of stakeholders to oversee implementation of the strategy. This Group will report to the Scottish Government and COSLA Health and Community Care Delivery Group. There will be a further line of accountability to the Ministerial Strategic Group on Health and Community Care. There will be different (but linked) arrangements in relation to implementation of the ***young carers*** part of the strategy as set out in that part.

ACTION POINT 1.1
The Scottish Government, with COSLA, will keep this strategy under review. An Implementation and Monitoring Group will report annually on progress, with the first report being undertaken by August 2011. A formal review will be concluded by August 2013. As part of the review the Scottish Government, with COSLA, and informed by the views of stakeholders, including carers, will decide whether new or revised Actions would be appropriate.

2. INTRODUCTION

Terminology

2.1 A range of terms is used to describe a person who cares for another including: 'unpaid carer,' 'carer,' 'family carer' and 'informal carer.' All partners involved in the development of this strategy prefer to use the term 'unpaid carer' or 'carer.' In this strategy we abbreviate 'unpaid carer' to 'carer,' as do many organisations and carers themselves. It is important that carers are not confused with paid workers, who are sometimes incorrectly called carers too: paid workers are care workers.

2.2 Equally, carers are not volunteers. There may well be volunteers supporting the cared-for person and/or the carer, but they are not the carer.

What carers do

2.3 Carers provide care to family members, other relatives, partners, friends and neighbours of any age affected by physical or mental illness (often long-term), disability, frailty or substance misuse. Sometimes the cared-for person will have more than one condition. Some carers care intensively or are life-long carers. Others care for shorter periods. The carer does not need to be living with the cared-for person to be a carer. Anybody can become a carer at any time, sometimes for more than one person. Carers are now, and will remain, fundamental to strong families and partnerships and to resilient and cohesive communities. **The lives of carers and the cared-for are closely intertwined, but they are not the same.**

Who this strategy is for

2.4 This strategy will be of interest to those who can improve the lives of carers, in partnership with carers, and who can influence the support provided to carers. It is for decision-makers, managers and practitioners, especially in local authorities, Health Boards, the NHS, Community Planning Partnerships, Community Health Partnerships and in all statutory agencies involved in supporting carers.

2.5 The strategy will interest the National and Local Carer Organisations, condition-specific organisations and others in the Third Sector.

2.6 Those who support mainly ***young carers*** will be interested in *Caring Together.* Although there are important distinctions to be drawn between ***young carers*** and carers, there are similarities in the caring experiences. There are also important transition issues, especially with regard to support for ***older young carers aged over 18.***

2.7 The strategy will also be of interest to unpaid carers in Scotland. We do not need to change carers' hearts and minds because they are acutely aware of what caring means. However, we do need to change how services and support are planned and delivered and take forward action which will benefit carers now and in the future. This strategy, together with other policies, will seek to achieve this.

"I am actually quite proud to be a carer. It's not something I would have chosen to do but my philosophy has always been, if you are going to do something, do it well."

Paul, who is a carer for his wife with MS and for his daughter with cerebral palsy.

Vision into Action

2.8 To advance this strategy and to build on and improve support to carers, it is necessary to articulate a clear vision of the future for carers.

2.9 Many carers say that it is a privilege to care for a loved-one and that caring brings rewards and a great deal of satisfaction. However, being a carer means that a loved-one, friend or neighbour is ill or frail or has a disability or a substance misuse problem. This can have a significant impact on carers' lives. Sometimes carers look after family members and others in very difficult and challenging circumstances, and because they feel obliged rather than because it is what they want to do. Statutory and Third Sector agencies providing services to the cared-for person should never assume that people want or choose to be carers and should also not make assumptions about the time commitment people have for caring.

2.10 Carers, whatever their circumstances, should enjoy the same opportunities in life as other people without caring responsibilities and should be able to achieve their full potential as citizens.

2.11 Our shared vision is a society in which:

- **Carers are recognised and valued as equal partners in care.**
- **Carers are supported and empowered to manage their caring responsibilities with confidence and in good health and to have a life of their own outside of caring.**
- **Carers are fully engaged as participants in the planning and development of their own personalised, high-quality, flexible support and are not shoe-horned into unsuitable support. The same principle applies to carers' involvement in the services provided to the people they care for.**
- **Carers are not disadvantaged, or discriminated against, by virtue of being a carer.**

2.12 The vision is underpinned by the mutual health and social care approach. In its broadest sense this means an inclusive Scottish society in which carers are reaffirmed as partners and are not passive recipients of health, care and other support services. The knowledge and skills of carers need to be harnessed to make decisions about the shape and structure of services.

Outcomes

2.13 This strategy will seek to achieve and sustain a number of key outcomes. **Carers will**:

- **Have improved emotional and physical well-being.**
- **Have increased confidence in managing the caring role.**
- **Have the ability to combine caring responsibilities with work, social, leisure and learning opportunities and retain a life outside of caring.**
- **Not experience disadvantage or discrimination, including financial hardship, as a result of caring.**
- **Be involved in planning and shaping the services required for the service user and the support for themselves.**

2.14 The particular needs of certain groups of carers, for example, carers who are older, Black and Minority Ethnic (BME) or Lesbian,

Gay, Bisexual and Transgender (LGBT), and carers with disabilities, will be recognised and supported.

2.15 Good outcomes for carers are dependent on a number of other factors including, crucially, the **provision of good quality services for the person they are caring for.**

2.16 The carer outcomes above are directly linked to the Government's National Outcomes, in particular:

- We live longer, healthier lives.
- We realise our full economic potential and more and better employment opportunities for our people.
- We have tackled the significant inequalities in Scottish society.
- Our public services are high quality, continually improving, efficient and responsive to local people's needs.

2.17 Key drivers for change include tackling health inequalities, improving people's mental health, maximising household income and promoting employment and lifelong learning opportunities.

Key role of carers: now

2.18 Carers play a crucial role in the delivery of health and social care provision in Scotland. The identified 657,300[1] carers in Scotland – 1 in 8 of the population - are an essential part of the workforce, in its broadest sense, contributing savings to health and social care services in Scotland of an estimated £7.68 billion[2] every year.

> ***"We are a good thing, a fundamental building block of society, and through our efforts we save the public purse billions of pounds."***
>
> Paul, who also provided the first quote.

2.19 Carers, as <u>equal</u> partners in the delivery of care, enable people with illnesses or disabilities to remain at home and in their own communities safely, independently and with dignity. Carers can, for example, prevent avoidable hospital admissions and contribute to people's overall health and well-being.

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[1] Scottish Household Survey, 2007-08
[2] Carers UK/University of Leeds, Valuing Carers, 2007

Key role of carers: future

2.20 Carers' role and contribution will be critical in the future due to demographic and social changes:

- Scotland's 65+ population is projected to rise by 21% between 2006 and 2016 and by 62% by 2031; and
- For the 85+ age group, a 38% rise is projected by 2016 and by 2031 the increase is a projected 144%.

2.21 By 2031 there will be larger numbers of very old people and a proportionately smaller, younger working and tax-paying population. This is a success story in terms of health and well-being, but it carries huge implications for the future of care in Scotland. There will be an additional 25% demand for health and social care services by 2031.

2.22 There will be more people living alone – an estimated 400,000 by 2031. More older people will also be living in remote and rural areas.

2.23 Older people provide far more care than they receive and are a major strength and resource, contributing much to society. With the ageing population, the number of carers is expected to grow to an estimated 1 million[3] by 2037. Three out of five people in Scotland will become carers at some point in their lives. Some older carers may require more support in their own right. **Society as a whole will become even more dependent on carers' vital contribution to health and social care delivery**. **Carers are at the heart of the solution.**

2.24 Shifting the balance of care from residential and institutional settings to care at home and more people being cared for at home for longer has implications for carers. Carers will play an increasingly important role in the support, care and treatment of people with long-term and/or multiple conditions, disabilities, illnesses, including dementia, and alcohol and drug dependency. **However, this greater role must not place additional burdens on carers or prevent them from working, learning or having a life outside of caring.**

[3] Carers UK

2.25 The age structure of the established BME communities is markedly different to the white population, with a much younger age profile. However, this will change within the next 10 years as the number of BME older people increases. This shift in the age profile presents an opportunity to provide suitably tailored and proactive support to BME carers.

2.26 There are other changes, for example, 'delayed motherhood' where an increase in births to women aged 40 and over might mean more younger people caring for elderly parents in future years.

2.27 There are also more children with complex and exceptional needs being cared for at home by parent carers. This is due, in part, to population increases but also to medical advances and to increased diagnosis and reporting. In Scotland there are approximately 70,000 disabled children under the age of 16.[4] For the first time, there is a generation of people with learning disabilities and complex needs who are outliving their parents.

2.28 There is a relatively new migrant population, including asylum seekers. Updated figures on the new migrant population will be provided in the 2011 Census. Many carers who have recently settled in Scotland do not generally access support for their caring role. Identifying these carers and providing support is important.

The case for action

2.29 Over the last few years, much has been achieved in taking forward the carers' agenda at a policy level both nationally and locally. There has also been real progress in providing practical support to carers. However, policy developments have not always resulted in real improvements in carer support,
leading - sometimes - to a breakdown in trust between carers and decision-makers and service planners. This strategy is therefore being published with a high expectation of change.

Much more needs to be done to achieve practical support on a consistent and uniform basis.

[4] Extrapolated from UK figure of an estimated 700,000 children, Family Resource Survey, ONS

2.30 Providing support to carers makes **economic sense** by saving resources in the longer term. With appropriate and timely support carers are able to care for longer, and enjoy better health and improved well-being. Carers do not usually 'down tools,' but unsupported they can experience real hardship financially, physically and emotionally. It is much more likely that a cared-for person will be admitted to hospital and the carer's own health deteriorate if the carer is unsupported. Carers can easily reach crisis point without **appropriate and timely intervention**. Such interventions can:

- **Maintain carers' capacity, reducing the need for paid service delivery to the cared-for person; and**
- **Help keep carers healthy, reducing their own need for support from the health and the social care system.**

2.31 Local partnerships between health and social care, with carer involvement, can **drive change at local level**. Some changes required could be achieved by **improvements to existing services and supports**, rather than requiring the development of new interventions. For instance, well-planned hospital discharge can result in **efficiency** savings.

2.32 If hospital discharge is well-planned and the right services put in place then there is a much greater likelihood of the cared-for person remaining at home with carer support. This means identifying the carer at an early stage when the person is admitted to hospital and ensuring that the carer is part of the care and discharge plan.

2.33 Although carers should receive support to help sustain them in their caring role, **they are providers of services, not service users.** This is an important distinction, and one which carers are keen to maintain.

2.34 The impact of caring can be immense:[5]

- Intensive caring can result in carers being twice as likely to suffer from ill-health as non carers.
- Up to 70% of carers will hide the fact that their health is suffering.
- One in five give up work to care.

[5] Carers in Crisis (2008), Carers UK

- 46% need to see a GP due to the impact of caring on their own health.
- Many carers are isolated or experience poverty of opportunity.
- Sometimes, the financial impact of caring can be acute (for example, by requiring additional heating, paying for special diets, refurbishing the home damaged by a child with autism and spending more on transport, especially in remote and rural areas).
- Where spouses or partners provide caring support to each other and where one person in the partnership falls ill or experiences an adverse event, this can result in both being admitted to hospital at much greater cost to health and social care budgets.

"Caring for our son was placing a strain on our relationship, our employment and our health. We were both physically and mentally exhausted. We never had a holiday without the stress of caring for our son."

Mary and her husband, who care for their 18 year-old son who has autism, a learning disability and challenging behaviour.

The evidence

2.35 The available evidence base points to **current and future savings across health and social care** arising from effective carer support:

- Training for carers can enable patients, especially those with chronic long-term conditions, to be supported longer within the community; and for older people it can delay a move to residential care.[6]
- Improving skills of carers during the rehabilitation of in-patients reduces costs for stroke care and improves their quality of life without increasing the burden of care to families or transferring costs to the community.[7]
- Carers provided with training are less likely to present at GPs with their own health issues.[8]

[6] Carers UK
[7] British Medical Journal: Training Care Givers of Stroke Patients: Economic Evaluation, 2004
[8] Hirst, Michael, *Hearts and Minds: the health effects of caring* (2004), University of York and Carers Scotland

- A recent report in England[9] exploring the social and economic benefits of short breaks provision aimed at those with the most complex needs (families with disabled children) estimated financial savings for the state of £174 million each year. This could be achieved through the effective delivery of short breaks combined with a range of activities, including extra-curricular and other activities in which disabled children can participate. The estimated financial savings for the state from full coverage of short breaks provision and other activity aimed at disabled children would include savings from less being spent on long-term residential care and health services. **A key message is that families should have *regular* short breaks to sustain their health and well-being and to maintain savings to the state.** Carers in Scotland say they benefit most when they have good quality, flexible respite as and when required.
- Providing telecare to people can result in savings to health and social care by reducing personal health problems as well as reducing unplanned admissions to hospital and admissions to residential care.[10]

The personalised approach

2.36 Ensuring a **personalised approach** can help support change. Each caring situation is unique. However, carers - whatever their caring situation - require similar types of support but personalised to the caring situation and responsive to particular needs and individual circumstances.

2.37 Building on 'Changing Lives,'[11] the Association of Directors of Social Work (ADSW) has given a clear commitment to advancing personalisation, recognising that more of the same will not work.

2.38 The personalisation approach is seeking to influence policy and local practice, promote innovation and empower frontline staff. ADSW will be engaging with managers in local authorities in order to achieve wider change in culture, systems and processes that will benefit both carers and those with care needs. Of course

[9] The Social and Economic Value of Short Breaks, nef Consulting, December 2009
[10] A Weight off my Mind: Exploring the Potential Impact and Benefits of Telecare for Carers, 2009 – University of Leeds and Carers Scotland
[11] Changing Lives: Report on the 21st Century Social Work Review
http://www.scotland.gov.uk/Publications/2006/02/02094408/16

advancing personalisation – moving towards more personalised supports – is a shared agenda relevant to all sectors and across all services.

ACTION POINT 2.1
Councils, with partners in NHS Boards, the national carer organisations and other Third Sector organisations, will continue to promote personalisation, working towards a position whereby staff at all levels receive induction training and continuous professional development on this approach, including having specific regard to the personalisation of carers' support (also see chapter 14 on training).

Resources

2.39 Resources for services to people with care needs and for support to carers are within local authority social care budgets. Other local authority budgets will also be relevant, especially in relation to housing and education.

2.40 The National Health Service (NHS) in Scotland is also responsible for providing health services to people with health care needs and for support to carers.

2.41 Local authorities' net revenue expenditure on support for carers, including respite care, was: £100 million in 2006-07, £117.034 million in 2007-08 and £134.740 million in 2008-09.[12] In addition, other organisations such as Alzheimer Scotland have received grants to help support carers.

2.42 Since this Government took office in May 2007, it has invested at least £15.814 million in support to carers and young carers. Some of this carries forward to 2011. The breakdown of financial support from the Scottish Government is set out in **Appendix 4.** The considerable level of investment in the telecare programme (over £20 million since 2006) also benefits carers.

2.43 The BIG Lottery announced in March 2010 that £50 million would be available from 2011 to support people with dementia and

[12] When comparing revenue expenditure levels in 2008-09 to previous years, there was a change to the local government funding structure in 2008-09, with the former ring-fenced revenue grants being rolled up into General Revenue Funding. As a result of this change, the figure in 2008-09 is not wholly comparable with the previous years' figures.

their carers and young people leaving care. While lottery funding decisions are taken independently of Government, the Scottish Government is working closely with the BIG Lottery Fund on this initiative.

Challenges

2.44 This strategy is being published in a difficult economic climate, with pressures on public finances and at a time when the population is ageing significantly. It is difficult to predict with certainty the duration of the economic difficulties. However, public spending will be under considerable pressure over the next few years.

2.45 **Despite the economic challenges, local authorities and Health Boards will commit to delivering incremental improvements in support for carers, recognising that demand on statutory health and social care provision is unsustainable without changes in the pattern of service delivery.**

2.46 **Service redesign, while necessary, has the potential to adversely affect the health and well-being of carers, if they do not have access to appropriate support.**

Opportunities

2.47 Support for carers is an essential part of key strategic developments such as the Reshaping Care for Older People programme, Shifting the Balance of Care, Scotland's National Dementia Strategy[13] and the programme of work on Independent Living, all being taken forward by the Scottish Government with its partners. The Scottish Government, local authorities and Health Boards, with key partners, can optimise the use of resources and harness the effort better by stronger strategic planning and more joined-up approaches to carer support.

2.48 Within existing financial resources, reducing avoidable hospital admissions by providing appropriate support and services in the community is the single most significant area that can deliver better outcomes for people. It also has the potential to release resources to use elsewhere in the health and social care system.

[13] http://www.scotland.gov.uk/Topics/Health/health/mental-health/servicespolicy/Dementia published on 1 June 2010

2.49 A philosophy of care that promotes people's independence and control of their situation by using current resources to optimum effect will reduce, but not eliminate, the need for additional resources to support carers.

Role of Scottish Government, COSLA and partners

2.50 The Scottish Government's role in respect of support to carers is to set out the strategic context, as we have done in this strategy. The strategic context provides the reference point, on a Scotland-wide basis, for local authorities, Community Planning Partnerships, Health Boards, Community Health Partnerships, statutory agencies and the Third Sector to locate their plans of action. The Scottish Government's lead in this area will be important to help support local implementation.

2.51 COSLA is the Scottish Government's formal partner in the development of this strategy. COSLA's leadership will be important to support local implementation.

2.52 Local authorities are responsible for decisions made at local level and they are best placed, with partners, to determine local priorities.

2.53 Given the evidence about demographic and social changes and the pivotal role of carers in sustaining care in the community, the Scottish Government and COSLA expect local authorities to have regard to the key messages in this strategy and to implement the Action Points relevant to them, as local priorities dictate.

2.54 As NHS Health Boards are accountable to Ministers, it was not appropriate or necessary for them to have the same formal partner status as COSLA in the development of this strategy. However, they were of course vital contributors to the work on the strategy. The Scottish Government expects NHS Boards to support implementation of the strategy as set out in the Action Points. **Health Boards are expected to make further progress and to take forward beyond March 2011 the good practice in the Carer Information Strategies (CIS), which the Scottish Government funded to March 2011.**

2.55 The Scottish Government cannot determine the priorities of the Third Sector, although we may influence them through Scottish Government funding to voluntary sector organisations to support

carers. However, we encourage the Third Sector to consider and take forward the Actions within this strategy to support carers. In particular, the national carer organisations have a key role in implementing the strategy, and some of the Action Points are specifically aimed at them.

2.56 The Scottish Government expects local authorities, Health Boards, Community Planning Partnerships and Community Health Partnerships to directly involve a wide range of partners, including Alcohol and Drugs Partnerships, in decisions about planning and delivering support to carers.

2.57 **The Scottish Government values the work of those statutory and Third Sector organisations which actively support carers. To reinforce and build on that work, across all of the statutory sector and relevant Third Sector agencies, the Scottish Government expects a change in culture so that it is everyone's job to actively identify and support carers.**

Baseline Position

2.58 In order to evaluate progress in support for Scotland's carers over the next 5 years, it is necessary to establish a baseline position as at 2010. Nationally, there is one key area where information is collected systematically. This is:

- **The number of respite weeks provided each year.**

2.59 The number of respite weeks provided in 2008-09 was 193,650[14] across Scotland (with many local authorities using a new methodology to calculate their respite weeks). The 2009-10 figures will be published later in 2010 and will be comparable with the 2008-09 figure. Thereafter the Scottish Government will collect the figures from local authorities every year. **The baseline position in 2008-09 is 193,650 respite weeks.**

2.60 Under the Community Care Outcomes Framework, local Community Care Partnerships are encouraged to collect data against 16 inter-related measures. These include measures on:

[14] Respite Care, Scotland 2009 (Final Figures)

- **The % of carers who feel supported and capable to continue in their role as a carer;**
- **The % of carers who are satisfied with their involvement in the design of the care package for the person they care for; and**
- **The % of carers' assessments completed to national standard.**

2.61 The data is examined and used for benchmarking purposes by the Community Care Benchmarking Network. A large proportion of partnerships are already using these measures and others are in the process of introducing them. The Scottish Government anticipates that such reporting will spread across Scotland in due course. Where local agencies are already collecting data against these measures, this will be published locally.

2.62 In addition, the Community Care Benchmarking Network is currently running a peer-led project on carer outcomes which includes collecting data on the number of carers assessments carried out in each partnership area across Scotland. Data on this range of activities will be published as part of a report on the project in Autumn 2010.

ACTION POINT 2.2
The Scottish Government will publish on its website each year the baseline position on respite support to carers and the position in all years up to 2015.

ACTION POINT 2.3
Each year, participating local partnerships will collect the relevant data on outcome measures relating to carers in the Community Care Outcomes Framework and will publish progress against the three outcome measures.

Good Practice

2.63 The Scottish Government has received a wide range of good practice examples/case studies from the statutory, voluntary and private sectors. These good practice examples demonstrate the commitment of local authorities, NHS Boards, the Third Sector and the private sector to ensuring support for carers in a meaningful and sustainable way.

2.64 It is not possible to showcase all the good practice examples in this strategy. **We are therefore publishing in a separate document the good practice examples received, as well as examples of good practice within the NHS Boards' Carer Information Strategies**. We make reference in this strategy to some of the examples. The full transcripts are in the separate document.

2.65 The challenge is to spread the good practice, recognising that local variation is sometimes necessary to reflect differing populations, geographical considerations, the existence of services already in place and so on. Certainly, some of the examples such as **e-learning modules for NHS staff** in one area can be rolled out at very little cost, and with high impact. **A high proportion of healthcare practitioners in Lothian have received training in carer awareness through NHS Lothian's e-training programme.**

2.66 However, to achieve consistent, high quality standards and approaches across the country, it is not enough simply to copy a service or support that works in one area. What is required to produce good outcomes for carers is an understanding of the changes needed to existing services and supports to make them more effective and efficient, and a commitment by decision-makers to implement these changes.

ACTION POINT 2.4
Over the next 5 years, councils and Health Boards, with partners, will take account of good practice promoted in local authority and Health Board areas. They will consider how the good practice can be transferred, if appropriate, and/or will consider whether or how existing services and supports can be reconfigured to achieve the best outcomes for carers and for those they care for. As a first step, councils and Health Boards, with partners, will consider the good practice contained in the publication accompanying this strategy.

ACTION POINT 2.5
By 2015, the Scottish Government will ensure that the planned acceleration in pace of sharing good practice under Reshaping Care takes account of good practice in supporting carers.

Care 21: The Future of Unpaid Care in Scotland

2.67 The Care 21 Report[15] made 22 recommendations about support for carers and young carers. The then Scottish Executive gave detailed consideration to each recommendation and provided a response in April 2006[16]. This strategy builds on the 22 recommendations in the Care 21 report. The 22 recommendations are set out in **Appendix 5,** which also details the progress made since 2006.

[15] The Future of Unpaid Care in Scotland, 2006
[16] Scottish Executive Response to the Care 21 Report: The Future of Unpaid Care in Scotland

3. PROFILE OF CARERS

The purpose of this chapter is to provide key data on the characteristics of Scotland's carers. It is necessary to have up-to-date data for planning, shaping and delivering support.

3.1 There are an estimated 657,300 carers in Scotland (Scottish Household Survey (SHS) 2007-08. The number of carers by local authority area are set out in **Appendix 6.**

3.2 **Caring requirements:** The SHS 2007-08 estimates that there is a person requiring care in around 14% of households. However, 33% of households report that there is a person in the household with a long-term illness or disability.

3.3 **Prevalence of caring:** Around 10% of the population provides care to another person. (Census 2001).

3.4 **Number of carers:** 79% of households with carers in them have one carer, 17% have two carers and 4% have 3 or more carers providing care in the household (SHS).

3.5 **Who carers care for:** The majority of carers provide care to a parent, closely followed by care to other relatives (spouses, children, siblings) (SHS).

3.6 **Time spent caring:** Almost half of Scottish carers providing care to other household members were providing 'continuous care.' 23% of all carers are caring for 50 hours or more. 63% of carers were undertaking less than 20 hours of care each week.(Census 2001). For those carers helping or caring for another person not living with them, 79% reported that they were providing less than 20 hours of care each week (SHS).

3.7 **Duration of caring role:** For those undertaking a caring role within the household, over 70% of carers have been providing care for over 5 years (SHS).

3.8 **Age:** As carers get older they take on more caring responsibility (Census 2001).

3.9 **Gender:** The data indicates that around 11% of women are undertaking a caring role, compared to 8% of men. The overall prevalence of women carers to male carers is around 60:40

(Census 2001). Between the ages of 30 and 69, more women are carers but the gender balance is more even for **young carers** and for older carers aged 70 and over when a caring role is undertaken within the household (SHS).

3.10 **Ethnicity:** All of the data suggests the difficulty in understanding the numbers of BME carers in society. Low reported numbers of carers should not be assumed to mean low prevalence of caring, but rather a reflection of the difficulties survey research has in adequately representing these groups.

3.11 The Minority Ethnic Carers Older People's Project (MECOPP) has undertaken a survey of support and services provided to BME carers by local authorities and Health Boards in Scotland. The report will provide data to support the baseline of information currently being established by the Scottish Government.

3.12 **Economic Activity**: For carers in employment, part-time workers are the most likely to be carers. Of those who undertake over 20 hours of care each week, part-time workers and unemployed people are the predominant carer groups (Census 2001).

3.13 **Working Status:** The working status of a household least likely to contain a carer who cares for another household member is single working adult households. The status of households most likely to contain a carer is a couple household where neither works (SHS).

3.14 **Social Class:** The socio-economic classification least likely to have a carer who cares for another household member is the higher managerial and professional occupations, at around 7% of households. Households with a carer are most likely to be in the lower managerial and professional occupations class (26%) (SHS).

3.15 **Scottish Index of Multiple Deprivation (SIMD):** The biggest proportion of households with a carer who cares for another household member (28%) are in the 20% most deprived data zones in the SIMD. The proportion of households with a carer then decreases steadily as deprivation decreases, so that the least deprived 20% of data zones also has the lowest prevalence of households with carers in Scotland (13%) (SHS).

3.16 **Housing tenure**: Carers who care for other household members are most likely to own their property outright (35%), which is likely to be linked to a tendency for carers to be older and/or retired. A further 33% of households with a carer socially rent their property (SHS).

ACTION POINT 3.1
The Scottish Government will make the information on carers and *young carers* from surveys such as the Scottish Household Survey and Scottish Health Survey accessible to researchers, care providers and the public through its website and publications.

ACTION POINT 3.2
In respect of the 2011 Census, the views of carers' organisations will be taken into account in deciding what analysis tables will be produced for the General Register Office for Scotland 2011 Census website.

Diversity of the caring population

3.17 Carers reflect the diversity of Scotland's population. There are carers who work, carers who cannot work due to their intensive caring or age, carers who want to work or pursue opportunities in Further or Higher Education, older carers and ***young carers*** under 16, lone parent carers, lifelong carers, student carers, BME carers, LGBT carers, carers in remote and rural areas and many other types of carer. Of course, carers may fall into more than one category.

3.18 **Kinship carers** are different from carers in that they are the family and friends of young people who are in, or are at risk of coming into, the care system. Kinship carers are sometimes the parents of adults with substance misuse problems who care for their grandchildren. They should receive a kinship care allowance from the local authority. However, a kinship carer can also be a carer if, for example, the grandchild has a disability and/or if the kinship carer is also caring for their partner, own parent or someone else. **Therefore, support for people who are kinship carers through the carers' route should always be considered if appropriate.**

Diversity of the cared-for population

3.19 Just as carers are diverse, so too are the people they care for. It is not straightforward to categorise caring situations. For example, a person with dementia may also be frail and elderly or a person with a learning disability may also have a mental health problem. There are many people being cared for who have long-term conditions.

3.20 The Scottish Consortium for Learning Disability (SCLD) is working with local authorities to ensure the gathering of more accurate statistics on adults with learning disabilities and autism. The 2008[17] figures show that 7,793 adults with learning disabilities and autism known to local authorities in Scotland lived with a carer. This represents 48% of the adults for whom this information was reported.

3.21 There are some communities of carers we know very little about, most notably: refugees, asylum seekers, gypsy travellers and carers who themselves have disabilities, including learning disabilities. The Scottish Government will consider the need for research in this area.

ACTION POINT 3.3
By 2012, the Scottish Government will draw up a specification and seek to commission research on communities of carers we know little about, including refugees, asylum seekers, gypsy travellers and carers with disabilities, including learning disabilities. This is relevant to *young carers* too.

[17] Scottish Consortium for Learning Disability: eSAY project

4. PRIORITISING SUPPORT FOR CARERS

The purpose of this chapter is to make clear that carers most in need should be prioritised for support. This does not mean delivering support in response to crises. The emphasis should be on early intervention and preventative support. There is a link to chapter 3 on the profile of carers in that some further data is provided on carers' characteristics. Small packages of cost-effective support are appropriate.

4.1 There are carers who are particularly vulnerable and in need of support, especially preventative in nature. The estimated half of carers who provide care to another household member and who are caring continuously each and every day are caring intensively. Furthermore, the Scottish Household Survey 2007-08 shows:

- 18% of carers are aged 70 and over.
- 19% of carers are aged 60-69.
- 4% of carers care for two or more people.
- 70% of carers have been caring for over 5 years.

4.2 Another measure of 'need' might be those carers living in deprivation, who will be less able to pay for services, more likely to be in poverty and poorer health and more socially isolated.

4.3 Through review of their local strategies, local authorities with partners will wish to take account of the most vulnerable carers according to an objective assessment of need which also takes account of the nature and level of risk. The Scottish Government and COSLA acknowledge that authorities may already have done this.

4.4 This does not contradict the emphasis on early intervention or the preventative approach. What it does mean, for example, is that frail elderly carers might be considered to be in greatest need: a preventative approach would mean early identification of these carers and the availability of the necessary supports to enable quality-of-life and in turn to prevent crises.

4.5 There needs to be more focus on early intervention, with crisis support available too. In times of financial constraint the imperative is usually to take action when there is a crisis that

needs tackling. **However, a greater emphasis on anticipatory and preventative support in relation to both the carer and cared-for person – which does not have to be complex or expensive - can delay or prevent the need for crisis intervention, and is therefore more cost-effective.**

4.6 The Reshaping Care Programme has a strong emphasis on early intervention. A focus on anticipatory support for carers is essential as part of this programme.

4.7 Carers whose caring responsibilities are minimal also need to have adequate information so that they are supported should their caring responsibilities become more demanding, and possibly have 'emergency plans' in place should their circumstances change quickly.

4.8 No two carers or caring situations are identical. Carers in a similar caring situation - for example, caring for a grown up child with learning disabilities - may have different needs due to a range of circumstances, including the availability of services in their area, support from family and friends, support from the wider community, people's level of income to purchase services and so on. All these considerations are important.

ACTION POINT 4.1
By 2012, if they have not already done so, local authorities, with partners, will wish to revisit their local carer strategies to identify and support carers in need according to their own assessment of need. To support this process, the Scottish Government will produce a short list of key points that local carer strategies should address.

ACTION POINT 4.2
By 2013, local authorities, with partners, will aim to identify carers in greatest need according to an objective assessment of need, and in line with published indicators, which also takes account of the nature and level of risk. They will aim to provide support or signpost on to support.

ACTION POINT 4.3
Over the next five years, local authorities and Health Boards, with partners, should seek to provide preventative support to carers and minimise the need for crisis intervention.
ACTION POINT 4.4
Over the next 5 years the Reshaping Older People's Care Programme will look to ensure a focus on early intervention for carers. Good practice in this area will be transferred to other care settings.

5. EQUALITIES

The purpose of this chapter is to reinforce the importance of the equalities dimension in identifying and supporting carers. It is important to recognise, and to respond to, the particular challenges for some groups of carers. People should be free from disadvantage or discrimination as a consequence of caring.

As discussed in chapter 3 on the profile of carers, the lack of data on hard-to-reach or hidden carers, including BME carers, should not imply that they do not exist. This chapter also links to chapter 4 on prioritising support to carers and to chapter 6 on carers rights. We also include within this equalities chapter support to carers in remote and rural areas which is an equalities issue in terms of the availability of, and access to, services and support in certain geographical areas.

5.1 The new cross-cutting legislative framework, The Equality Act 2010, [18] is intended to protect the rights of individuals and advance equality of opportunity for all; to update, simplify and strengthen the previous legislation; and to deliver a simple, modern and accessible framework of discrimination law which protects individuals from unfair treatment and promotes a fair and more equal society. Chapter 6 on carers' rights covers in more detail the provisions in the Equality Act 2010.

Equality Groups

5.2 Ensuring equalities in race or ethnicity, disability, gender or sexual orientation, age or religion means **ensuring opportunity for all carers to access suitable resources and support.** Carers may be excluded from support because there is no recognition of their particular caring situation. The result may be lack of opportunity, difficulty in accessing provision or unresponsive services.

5.3 Support needs to be delivered in a sensitive way. So, for example, carer training might be delivered to BME female carers in their own right. In relation to gender issues, professionals have to recognise that daughters may not wish to carry out personal care

[18] Further information can be found at the Equality and Human Rights Commission (EHRC) website at: http://www.equalityhumanrights.com/

for their fathers. Carers' centres should deliver support to partners and be careful about advertising themselves to families only, which might be off-putting to LGBT carers. Health and social care professionals need to be sensitive to caring relationships and the different forms these may take.

"We were treated differently to heterosexual couples who meet in a private space during visiting times whereas we had to meet in the dining room of the hospital ward. One day when I put my arm around Martin to comfort him I was told to stop by healthcare staff as they thought this may lead to 'other things.' As a very private person I was extremely upset and humiliated."

Brian, who cares for his partner, Martin who has mental health problems.

5.4 There should be greater awareness in delivering culturally competent services. Cultural competence[19] as a concept has evolved particularly in relation to BME groups but it applies equally to other equality groups and all forms of social care.

5.5 Cultural competence recognises that there are barriers which effectively prevent BME carers and service users accessing appropriate support and services. These barriers may be visible, such as producing information in English only, or invisible, such as the assumptions of individual workers which may lead to cultural stereotyping.

[19] The Scottish Government defines cultural competence as: 'a service which recognises and meets the diverse needs of people of different cultural backgrounds. A key part of cultural competence is ensuring the discrimination on the basis of culture, belief, race, nationality or colour has no role in the delivery of services.'

"I look after my wife myself. Our children have grown up and moved away. It is very difficult and tiring but I have to manage. I do not read or speak English so I did not know I could get any help until a Chinese worker told me. My life is easier now but there are still many Chinese who do not know they are a carer."

Mr Lim cares for his wife, who has had a stroke and is also frail elderly. (translated into English)

5.6 Problems in identifying BME carers can lead providers to believe that there is no need or demand for their services. Additionally, BME communities in different parts of Scotland can be relatively small, with an even smaller BME carer population. This may lead providers to believe that a 'critical mass' does not exist to justify the development of specific services. **Whilst it may not be practical or appropriate to develop new services, providers must consider whether they are excluding people from support that other carers receive.** The 'mainstreaming' agenda recognises that mainstream services have to change to accommodate the needs of a diverse population. 'Mainstreaming' is equally applicable to all equality groups.

5.7 There will be some carers who are themselves disabled. Their particular needs should be fully addressed by local authorities, Health Boards and other partners. This will be in line with the existing disability public sector equality duties.

5.8 **Equality Impact Assessments** can provide an important mechanism for increasing awareness of carers' needs and rights in the public sector. The public sector is required to ensure that equality duties on race, disability and gender are integrated into all the functions and policies of Scottish Government Directorates and Agencies and of local authorities and Health Boards. We all need to assess the impact of our policies to ensure that we do not inadvertently create a negative impact for equality groups.

ACTION POINT 5.1
The Scottish Government, with COSLA and partners, will ensure that all the Action Points in this strategy are taken forward in ways which fully address the equalities perspective.

Carers in Remote and Rural Areas

5.9 Providing support to carers in remote and rural areas has an equalities dimension to the extent that carers living in these areas may not have access to support that other carers have. We refer to the particular needs of carers in remote and rural areas throughout this strategy, especially in relation to the accessibility of services for the cared-for person, the provision of short breaks, carer training, carer health and income. The accessibility of healthcare services for the person with care needs is an issue.

5.10 Another key issue is transport. Many carers in remote and rural areas have to travel long distances and there are issues about the lack of adequate transport or the high costs of transportation. **Appendix 7** sets out the full range of Scottish Government policies **designed to improve transportation in remote and rural areas.**

"Living in a rural area we rarely go out other than for medical appointments due to fuel and time costs. Shopping and seeing friends is always squeezed into these travel arrangements.
Doctor 68 miles return (1 hour 30 minutes), hospital 140 miles return (3 hours)."

Ann, who cares for her husband with complex health problems and limited mobility.

5.11 Community transport services[20] are normally operated by voluntary organisations and can take different forms such as community minibuses, dial-a-bus, and voluntary car schemes.

[20] Local authorities may be able to provide information on community transport services operating in their area. In addition, the Community Transport Association , Tel 0870 774 3591 or e-mail ctascotland@ctauk.org, may be able to provide details of community transport services in rural parts of Scotland.

These types of service are very valuable in rural areas where there are no or very limited, public transport services and are of particular benefit to older and disabled people. Many services are demand led, providing a door-to-door service at the time requested by the passenger. This type of service may be of benefit to carers, particularly in rural areas.

5.12 There are other key issues relevant to caring in remote and rural areas. As a result of having to travel long distances, it can be difficult to keep hospital and GP appointments. Innovative solutions are needed to help make life more straightforward for carers in rural areas. Telehealthcare solutions are very relevant to caring situations in remote and rural areas. Telephone support in relation to health and well-being and carer training should be explored further. The development of rural co-ordinating networks, perhaps to facilitate respite, can help. The further development of community facilitators or co-ordinators of support in remote and rural areas can be explored too.

ACTION POINT 5.2
From 2010 onwards, the Scottish Government will work with the relevant local authorities, Health Boards and Third Sector organisations to develop plans to help address rural carer issues.

6. CARERS RIGHTS

The purpose of this chapter is to set out the Scottish Government's view on the development of carers' rights. Once commenced, the Equality Act 2010 will be an important step forward, as will the provisions in the forthcoming Self-Directed Support (Scotland) Bill. We emphasise that existing carers' rights (as enshrined in law) should be further enhanced by the development of a Carers Rights Charter, which will consolidate in one place the existing rights and will set out key principles of support to carers and outcomes. The Scottish Government will consider whether further rights should be enshrined in law.

6.1 The Equality Act 2010 will prohibit direct discrimination and harassment based on association and perception in respect of race, sex, gender reassignment, disability, sexual orientation, religion or belief and age in relation to employment and other areas. This legislation will cover cases where the less favourable treatment is due to the victim's association with someone who, for example, is disabled. The discrimination will be unlawful in relation to a person's employment and also through the provision of services and housing and in other areas.

6.2 The **Patient Rights (Scotland) Bill** aims to place patients at the centre of the NHS in Scotland. If approved by the Scottish Parliament, this healthcare legislation will help ensure that patients' rights and entitlements are more widely understood and used. As part of the requirements, there are expected to be Patient Rights Officers for Health Board areas. **This will have direct relevance to carers.**

6.3 The **Self-Directed Support (Scotland) Bill** will seek, amongst other things, to give local authorities the power to provide direct payments to carers.

6.4 Self-directed support is one form of personalised support which ensures individuals can choose how and by whom their support is provided. Evidence suggests that self-directed support and direct payments can lead to improved outcomes for individuals, families and communities.

6.5 The Scottish Government has consulted on a draft National Strategy on Self-Directed Support and is consulting on proposals for a Self-Directed Support (Scotland) Bill. One of the aims in the Bill would be to extend eligibility for direct payments to various groups that are currently excluded, including carers. The Bill would provide local authorities with greater flexibility so that they can provide support to carers in the form of a direct payment.

6.6 The aim is to remove barriers to people taking up self-directed support, including direct payments. Barriers to direct payments include: assumptions and attitudes about the characteristics of people who may benefit from them; limitations on the use of the allocated budget; and the challenges of sustaining current services whilst investing in new individualised approaches.

6.7 The use of direct payments can help meet the needs of certain sections of the carer population, including BME service users and carers. **The Minority Ethnic Carers Older People's Project (MECOPP) is supporting a group of BME carers and the people they care for in West Lothian to pool their direct payments together to facilitate support within mainstream daycare services.**

6.8 Current direct payments' legislation only allows direct payments to be used to employ a close family member in exceptional circumstances, "…where securing the service from such a person is necessary to satisfactorily meet the service users' assessed needs." It is important that this facility is made known to carers from the outset and is used where this could provide best outcomes, for example when:

- a person requires end-of-life care;
- there are few service providers in rural or remote areas;
- it is considered to be the most appropriate way of meeting an individual's cultural needs; or
- a feature of the person's disability is challenging behaviour towards strangers.

6.9 Carers' rights which are not enshrined in law can be taken forward in a number of different ways. In particular, as well as the provisions in this strategy relating to, for example, the provision of information and advice, carer training, short breaks and telecare, **the Scottish Government will also ensure that carer**

representatives are members of Community Health Partnerships (CHPs) – see chapter 7 for further details.

6.10 The Scottish Government intends to raise the profile of carers' issues widely through a Carers Rights Charter setting out and consolidating existing rights, what carers need to help achieve better outcomes and what local authorities, Health Boards and others need to do to support carers. A clear set of **principles** in support of carers will be established. The Charter will be widely distributed.

ACTION POINT 6.1
From 2010 onwards, the Scottish Government will work with the national carer organisations to promote the Equality Act 2010, once commenced, especially the provisions providing protection from discrimination for carers.

ACTION POINT 6.2
The Scottish Government will work with COSLA and local authorities to ensure a consistent approach across local authorities to the employment of close family members in exceptional circumstances. The guidance on implementation of the Self-Directed Support Strategy, to be produced by the Scottish Government, will include a section on approaches to the employment of close family members in exceptional circumstances.

ACTION POINT 6.3
By December 2011, the Scottish Government will produce, with COSLA and partners, a Carers Rights Charter for wide distribution to local authorities, Health Boards, Community Health Partnerships and other bodies. By July 2013, the Scottish Government will consider whether further rights should be enshrined in law.

7. CARER INVOLVEMENT IN PLANNING, SHAPING AND DELIVERY OF SERVICES AND SUPPORT

The purpose of this chapter is to set out how carers will be further involved in the planning, shaping and delivery of services and support. Their involvement is crucial to ensure the best quality services and support, delivered in a personalised way. Carers should be involved in a number of different ways.

7.1 **Community Health Partnerships (CHPs),** established by NHS Boards, have a role in delivering the change required to support the cared-for person and the carer. This is because they have to ensure that people and communities are engaged in the decisions made on health services which affect them.

7.2 CHPs provide an opportunity for partners to work together to improve the lives of local communities. CHPs should actively involve the public, patients and carers.

7.3 Some CHPs have carer representation on them, through carer organisations. Carers themselves are represented on Public Partnership Forums, which are one of the main links between communities and CHPs. Members of the Public Partnership Forums (usually Chairs and/or Vice-Chairs) generally have a place on the local CHP, and a number of carers currently fulfil this function.

The Scottish Government believes there should be carer representation on CHPs and will ensure that this happens.

7.4 **Public Partnership Forums** continue to provide a valuable input into the planning and delivery of local services and it is important that their role continues to evolve. As such, the Scottish Government will be undertaking a review of Public Partnership Forums so that their role can be strengthened and developed. **Given the important contribution that carers make to Public Partnership Forums through their expertise and knowledge, we are committed to involving them in the review so that their interests are fully represented.**

ACTION POINT 7.1

In 2010-11, the Scottish Government will ensure carer representation on CHPs by writing to the Chief Executives of Health Boards to make this happen.

ACTION POINT 7.2

In 2010-11, in taking forward a review of Public Partnership Forums, the Scottish Government will ensure that it consults with appropriate carer organisations in order that their interests are fully represented.

ACTION POINT 7.3
Local authorities and NHS Boards will ensure they fully involve the national carer organisations, other Third Sector organisations and carers, as appropriate in the planning and shaping of services and support.

7.5 Carers will continue to be involved in **inspections** of services when the new scrutiny bodies, Social Care and Social Work Improvement Scotland (SCSWIS) and Healthcare Improvement Scotland (HIS), are set up in 2011.

7.6 **The Healthcare Quality Strategy for NHSScotland**, published in May 2010[21], will also help ensure the voice of carers is heard. It is the key driver for further change and improvements in healthcare. This strategy will seek to ensure that healthcare is of the highest quality, with improved safety and clinical effectiveness based on person-centred support and the full involvement of care partners. There will be an emphasis on developing relationship-based care and shared decision-making. A further aim is to ensure that patients and carers have clear instructions and information on care, treatment and symptoms and that they are fully involved in treatment choices. There will be a clear emphasis on treating carers as equal and expert partners with knowledge and experience, especially about the person they care for.

[21] http://www.scotland.gov.uk/Publications/2010/05/10102307/8

7.7 The Healthcare Quality Strategy lists National Quality Outcome Measures, some of which are of direct relevance to carers and ***older young carers*** and which help ensure carers have a pivotal role in decision-making. In particular:

- **Carers will provide feedback on their experiences of healthcare. The Scottish Government is considering how to capture the experiences of carers; and**
- **The measure on emergency admissions, relating to supporting patients to remain at home, will reflect improved partnership working with carers.**

7.8 Carer involvement and participation in **procurement processes** is essential to empower carers, and to ensure that services properly take account of carers' needs.

7.9 The Scottish Government expects to report on the consultation on Draft Guidance on Social Care Procurement in summer 2010. The Draft Guidance sets out a framework for social care procurement in Scotland which has a significant impact on people's quality of life and well-being.

7.10 Local authorities' commissioning strategies should set out the future response to meeting needs and improving outcomes and the plans for major shifts, such as moving control from organisations to individuals and moving from institutional/ buildings-based services to community support, where that is appropriate.

7.11 Local authorities should adopt an inclusive approach and create an environment which involves stakeholders, including service users, their advocates, carers, service providers and those with a statutory responsibility for service delivery, working together to improve outcomes for service users and carers.

7.12 Procurement processes have, in some cases, given service users and carers a sense that they have little control over their lives and no ability to impact on the decisions made in respect of their services.

7.13 The involvement of service users and carers, and the opportunity for them to voice their experiences and views, is essential at every main stage of the procurement process, from the

earliest stages of analysis and planning to the later stages of contract monitoring, management and review. Service users and their carers may have an opinion on changes to current service provision, may have concerns about an existing provider which merit a change of provider, or may want to support the continuation of a service provided by the local authority or voluntary or private sector.

ACTION POINT 7.4
In 2010 and beyond, the Scottish Government and COSLA will promote the Social Care Procurement Guidance to local authorities so that they are aware of that part of the guidance on carer participation and can act on it as appropriate. Furthermore, the Scottish Government will provide training for procurement staff, establish learning networks and promote good practice to continue to seek improvement in procurement practices across Scotland, which will take account of the need to involve carers.

7.14 Carers should be involved, as appropriate, in the **care plans** for the people they care for. For example, with regard to carers who care for people with mental health problems, psychiatric services need to ensure that they involve the carer as much as possible in the care and treatment plan so that the carer can be fully supported and engaged. This can be a difficult area for all concerned if the adult refuses to give consent to share personal information with carers, as is their legal right. In these circumstances, professionals must respect the need for professional confidentiality, whilst maintaining an open professional relationship with carers as interested parties.

8. IDENTIFICATION OF CARERS

The purpose of this chapter is to set out the measures to take forward effective carer identification by ensuring that the health and social care workforce have the necessary skills. Self-identification is also important. Identification is the precursor to a carer's assessment and to receipt of support. Appendix 8 sets out a carer pathway from carer identification or self-identification through to support.

8.1 There are a number of different ways to identify carers. Different models have been tried and tested and two lessons have emerged as the most effective way of identifying carers:

- It is widely recognised that practitioners in the NHS and social care professions are best placed to identify carers through their contact with patients and their families; and

- Integrating carer identification into the core professional role of health and social care professionals supports effective carer identification and signposting to support.

8.2 Once identified, a carer may not want to be over-burdened with information. As their caring role changes, they may require a certain level or different type of information. Mental health carers tell us that many of them need information at the pre-diagnosis stage, especially if their relative seems to have severe problems and erratic behaviour, but where there is no diagnosis as yet.

8.3 It is important to keep a focus on carer identification, as this is the first important step to having a carer's assessment and also to accessing appropriate support to meet carers' needs. As part of this, **there needs to be a continued emphasis on carer identification within GP practices and in hospital and other settings.**

Perth Carers Centre said:

Usually when someone cares for someone with a long-term condition, the care professionals are maintaining the cared-for person and they do not always offer the carer support automatically - this is changing as they are more aware of the needs of carers through networking meetings, conferences being held and so on. Also staff working in the GP practices and raising the profile of our carers centre enables these people to come forward for support and for health care staff to recognise carers centre staff and how they provide carers with support.[22]

8.4 Carers were included in The Scottish Enhanced Services Programme for Primary and Community Care (2007-2009). This programme will continue until April 2011. The enhanced services are maximising the opportunities to identify carers through the work of general practice and by understanding the carers' role and its associated risks. This enables the practice team to support carers in their caring role and to help carers protect their own health. GP practices providing these services are expected to establish a structure to support the overall needs of patients who are carers.

8.5 NHS Boards have developed strategies to identify carers and many are doing so. **For example, in South Lanarkshire a Primary Care Co-ordinator works with the 55 GP practices to identify and support carers. A Blood Borne Virus Support Worker identifies BME carers, some of whom are affected by BBV. A GP Liaison Worker in NHS Borders works with GPs to help identify carers.**

The Scottish Government expects NHS Boards to maintain a focus on carer identification through the Carer Information Strategies.

8.6 **The Princess Royal Trust for Carers has taken forward the Moffat Programme, sponsored by the Moffat Charitable Trust, with four NHS Boards – NHS Lothian, NHS Greater Glasgow and Clyde, NHS Ayrshire and Arran and NHS**

[22]PRTC Carer Centre Survey, 2010

Borders. The main aim of the Moffat Programme is to promote early identification, intervention and support for carers to prevent unnecessary crisis, including a breakdown in carers' own health.

8.7 **Carers Scotland is continuing to work with GPs and other primary health care personnel to raise awareness of carers, to help staff identify carers and to help carers self-identify. They have produced a resource pack for GP practices which provides a range of tools and a notice board. Carers centres across Scotland are working with GP practices too.**

8.8 The workforce training initiative set out in chapter 14 on carer and workforce training will help promote carer identification. The emphasis on training social care staff in the undertaking of carers' assessments set out in chapter 9 will be critical to this process.

8.9 There is scope for the Scottish Government to work with Alcohol and Drug Partnerships (ADPs) and with the new Scottish Drugs Recovery Consortium (SDRC) to promote the need for the identification of, and support to, carers of people with substance misuse problems. The Scottish Government expects ADPs to engage with all relevant aspects of community planning to help secure the best outcomes both for people with addiction problems and for their carers and families. The SDRC will be working closely with ADPs by assisting service user groups, family support networks and local communities. Carers of people with drug and alcohol problems can make an important contribution to the recovery of the people they are caring for, and the welfare of carers is an important part of this agenda.

ACTION POINT 8.1
From 2010 onwards, the Scottish Government will promote this strategy with Alcohol and Drug Partnerships (ADPs) and with the Scottish Drugs Recovery Consortium (SDRC) and will work with ADPs and with the SDRC to help identify and support carers of people with substance misuse problems.

8.10 The Royal College of General Practitioners Scotland has decided to make carer and ***young carer*** identification and support one of its key priorities in 2010-11 through its Patient Partnership in Practice (P3) group. This means that the RCGPS working with

others, will develop guidance for GP practices in Scotland on carer identification and support.

8.11 In addition, the RCGPS, in partnership with the Princess Royal Trust for Carers, is launching a UK-wide Award to recognise the excellent work of GP practices in identifying and supporting carers. These awards will be presented in the four UK countries, with an overall winner receiving the UK Award later in 2010.

ACTION POINT 8.2
The Scottish Government will approach all relevant national training and qualification accreditation bodies to agree how they could integrate carer identification and awareness into the curriculum by 2013.

ACTION POINT 8.3
In 2011-12 and beyond, local authorities, Health Boards and all carer support organisations are to identify carers and *young carers* in the hard to reach groups, including BME carers.

ACTION POINT 8.4
In 2010-11, the Scottish Government will work with the Royal College of General Practitioners Scotland on its plans to provide guidance to GP practices in Scotland on carer and *young carer identification* and support.

8.12 People can identify themselves as carers (**self-identification**). However, that is not straightforward. There is a widespread view that caring for or looking after someone, particularly a family member, is 'what you do.'

8.13 It can also be difficult to determine when 'the caring journey' starts, depending, for example, on the condition of the would-be carer's relative or partner, who may initially keep quite good health. As people become older, frailer, sicker, and/or increasingly disabled, become addicted to alcohol and/or illegal drugs or have a diagnosed mental health problem, the role of carer becomes more apparent.

"My sister constantly told me that I was a carer and that I should ask for help and for a long time I ignored her. I didn't think of myself as a carer and despite many visits to the GP and workers coming to see mum at home, no one had ever spoken to me about getting support for myself, so that reinforced my view that I couldn't get help."

Eileen, who cares for her mother, who has a combination of medical needs and is also frail.

8.14 Many people who support family members with mental health problems or drug or alcohol addiction do not seek to identify themselves as carers as there is still a stigma attached to this role. In addition, the person with care needs may deny that they need or are getting support from a family member or partner.

8.15 There are hard-to-reach or hidden carers, including BME and LGBT carers. For BME carers, problems of language and communication may make self identification more difficult. Professional attitudes and beliefs such as 'they look after their own' can also impact on how BME carers are identified by practitioners.

9. CARERS ASSESSMENTS (CARER SUPPORT PLANS)

The purpose of this chapter is to set out what the Scottish Government, local authorities and Health Boards need to do to improve the uptake and quality of carers assessments. These assessments can be called carer support plans, terminology which will enhance their accessibility to carers and reinforce the participatory and collaborative approach. All partners need to respond proactively to the concern that carers are often critical of their experience of professionals as assessors and gatekeepers to services. Carers want to have more control over the services developed and delivered to the person they care for, and over support for themselves.

9.1 Carers who provide substantial and regular care have a statutory right to assessment.[23] The strategy recognises that there needs to be improved uptake and delivery of quality assessments. In addition, those carers who are not eligible for a carer's assessment should, as far as possible, be provided with information, advice and pointers towards available community supports.

9.2 The Scottish Government, local authorities and Health Boards need to:

- Be proactive in ensuring that carers know about the right to request a carer's assessment and that up-to-date information on carers' support is available;
- Articulate and promote the value and benefits of a carer's assessment;
- Develop a wider understanding of the need for the carer's assessment, and its reach in considering all aspects of carers' lives;
- Increase access to carers' assessments and monitor the up-take;
- Ensure that there is an outcomes-based approach which does not shoehorn people into existing services if those services are not suitable; and

[23] Under the Social Work (Scotland) Act 1968, as amended by the Community Care and Health (Scotland) Act 2002, carers who provide "a substantial amount of care on a regular basis" are entitled to an assessment.

- Ensure that assessed needs are met and the impact and outcomes monitored.

9.3 Every person who is entitled to request an assessment of their ability to care, and who wants an assessment, should have a comprehensive assessment carried out quickly after requesting the assessment. The assessment should be reviewed systematically to take account of changing circumstances affecting the carer, cared-for person and other relevant people. The assessment should cover the need for emergency planning so carers have a plan to cover emergency situations. Those carrying out the assessment should be knowledgeable about the availability of supports to the carer and services for the cared-for and other relevant people. The carer should have a named person they can contact following on from the carer's assessment. Carers centres have a key role in promoting the assessment and in helping carers to make the most of the process.

9.4 The outcomes approach to community care seeks to embed user and carer experience at the heart of all community care services and support. One of its key principles is direct engagement with people using those services and their carers through the *Talking Points* approach to assessment, care planning and review.

9.5 The Scottish Government's review of *Talking Points* to date shows that many frontline practitioners are enthusiastic exponents of the approach. However, there is greater resistance amongst middle managers, who are concerned about raising carers' expectations, the time commitment required for the development of care plans, the need for continuous review of the care plans, lack of services to signpost carers on to and lack of resources. These are legitimate concerns.

9.6 Nevertheless, investing time in the carer's assessment will reap benefits. Those carrying out the carer's assessment and their managers need to be fully aware of the range of existing services in local areas and to have the ability to take forward personalised and flexible approaches to meet the needs of the carer. A staged approach to meeting the carer's needs might be appropriate, and if this is the case it should be fully explained to the carer, with the carer given the opportunity to comment.

9.7 There is guidance on the training and development of staff on the Scottish Government's Joint Improvement Team website at: http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/staff-development-materials/

9.8 The previous Scottish Executive issued Guidance on Sections 8-12 of the Community Care and Health (Scotland) Act 2002 (Scottish Executive Circular CCD 2/2003). The guidance covered, amongst other issues, informing carers of their right to assessment and the assessment of carers. It is still relevant, but we could usefully complement it with practical guidance to undertaking carers' assessments.

9.9 **Glasgow City Council has developed self-assessment for carers in partnership with a wide range of statutory and voluntary agencies. Edinburgh City Council has developed a new carers' assessment tool based on effective partnership working between the statutory and voluntary sectors. It is outcomes focused and meets the national minimum information standards. This is an electronic tool hosted on the single shared assessment platform, eAssess.**

9.10 **Those carrying out assessments and their managers must recognise that there are wider resources across a range of agencies, and the wider public sector, which can support carers following an assessment. With a wider focus, the assessment can lead to carers being signposted to services other than those traditionally within the remit of social services.**

9.11 However, the assessment process also presents an opportunity to document where resources, supports or services are not available. Assessors could do this to assist with strategic planning. It would help to identify unmet need.

ACTION POINT 9.1
On an ongoing basis, in order to fully engage carers and deliver improved outcomes for carers, the Scottish Government will continue to promote and monitor the use of carer outcome evaluations through *Talking Points.*

ACTION POINT 9.2
On an ongoing basis, in order to improve the knowledge and skills of the social care and health workforce in undertaking carers' assessments, the Scottish Government, in partnership with local authorities, will continue to encourage and promote the further training and development of staff. (Also refer to chapter 14 on training).

ACTION POINT 9.3
In order to improve the carrying out of carers' assessments with the aim of delivering improved carer support, the Scottish Government will, by 2012, commission the production of practical guidance on the undertaking of carers' assessments. This will include guidance on how to conduct culturally competent assessments. This will be done in partnership with COSLA and NHS Scotland and will be informed by stakeholders and carers.

ACTION POINT 9.4
On an ongoing basis, local authorities will monitor the impact and outcomes of carers' assessments. If any resources, supports and services are not available to meet need, local authorities will use the carer assessment process (and other initiatives) to record what is currently unavailable. This will assist strategic planning with respect to carers' support.

10. RANGE AND TYPE OF SUPPORT

The purpose of this chapter is to act as a link to the subsequent chapters on the range and type of personalised support to be made available to carers. The key issues raised at engagement events with stakeholders are set out here.

10.1 The carer's assessment/carer support plan should be the gateway to support and services. However, carers who do not have a carer's assessment/plan should also be able to access support even if the carer's assessment is the preferred route to support.

10.2 There are many forms of support available to carers over and above that provided, in some cases, by other family members, friends and neighbours. Carers who are new to caring often say that the priority for them is to have **information and advice** about the condition or illness of the person they are caring for. They may require a different type of information as the illness or condition changes.

10.3 In the delivery of support, it is important to take into account that a person's caring situation can change quite dramatically, even in a short space of time. People can continue to be carers, in a different way, for example, when the person they are caring for moves on to independent living or into a care home. Caring at end-of-life is particularly difficult and the carer may need support after their relative dies.

"I felt alone and in the dark when mum died. I loved caring for mum. But a carer's life starts to move on when their caring journey ends. I have now found my own identity as this can be lost when caring. My carers' centre supported me to see the light. I am carrying on using my voice and experience in supporting carers."

Rosemary, who cared for her mother with dementia. Rosemary's mother sadly died in February 2010.

10.4 Carers frequently report the difficulties they encounter and the barriers they face in their day-to-day caring role. Some say they have benefited from support which is then withdrawn or that there is a disjointed approach to the delivery of support from

different professionals. Carers themselves often have to use their limited and precious time and energy to facilitate the connections to be made amongst the various professionals.

"Our daughter has complex health and developmental needs. We had to come to terms with the fact that life was going to be very different for her and for us as a family. Services became disjointed when she was four years old. Getting assessment and support was an uphill struggle. We co-ordinate our daughter's support and we want the disjointed approach to end. The battle is exhausting for both sides."

Brett and Maggie, who care for their young daughter with a rare genetic syndrome (Cornelia de Lange Syndrome).

10.5 Carers often experience disjointed approaches and a lack of joint working at times of transition for example, when their child with a learning disability leaves nursery or school. The transition from children's to adult social care services can be particularly traumatic. Some carers have described this like "falling off the end of a cliff."

"Planning for transition can be spectacularly pointless if there is no follow-through. A multi-disciplinary group agreed that all of my daughter's support should continue as her needs would not change. But after transition to adult services, nothing continued and I was left to start things up again as best I could."

Anne, a lone parent who cares for her adult daughter with profound learning disabilities and who is physically dependent.

10.6 Equally, change can be managed well. Anne, above, also said:

> ***"The move into supported accommodation was managed very well. I was consulted about my daughter's care plan and social activities, equipment and furnishings. We met her flat mate and new care workers well before the move. A difficult and anxious time was made less so by a sensitive response to my concerns and a clear and continuing commitment to my daughter's well-being."***
>
> Anne.

10.7 **Early diagnosis** of a condition, syndrome or illness helps would-be carers to access information and advice at the earliest opportunity. For example, the Scottish Government's continuing national health target on improving early diagnosis of dementia recognises that this is key to those with dementia and their carers in accessing the gateway to early post-diagnostic support.

10.8 Caring can impact heavily on a carer's physical and/or mental health and well-being. Access to **emotional support** through a carers centre or provided by a condition-specific organisation or through the GP can help. Some carers need more intensive interventions such as **counselling**.

10.9 Good advice and person-centred training on **moving and handling** can help with the **physical aspects of caring**. So too can having the right services in place for the cared-for person to lessen the physical burden, which can sometimes be extreme.

10.10 Many carers benefit from **short breaks or respite.** This is linked to **emergency planning** – a rapid response service – when there is a need for such a service. Carers should be supported in proactive planning for emergencies and unexpected events.

10.11 **Carer training** is important. If carers have access to good quality training, they are better equipped to deal with many different aspects of caring and to continue in their caring role.

10.12 **Housing** and housing support is an important issue for some carers, especially in ensuring they have the right type of

accommodation to suit the needs of the family. Access to the right **equipment and adaptations** when needed is necessary.

10.13 Access to **telecare services** for the cared-for person can also provide peace of mind, reduce stress and lessen the physical aspects of caring.

10.14 Some carers, especially the most vulnerable, benefit from independent **advocacy support** to help them in many different ways, including supporting them in their dealings with health and social care and other professionals.

10.15 Many carers want support to remain in **work** as work provides an income and it is what people generally do, or want to do. Others want to access work, training or Further or Higher Education. Other carers who cannot work due to age and/or level of caring responsibility would like support to have a **good standard of living** and not experience financial challenges due directly to the costs of caring.

10.16 **Carers want to have an identity beyond caring which can be found in employment, volunteering and leisure opportunities.**

10.17 Carers appreciate the support provided by **carers centres** and by a wide range of voluntary organisations and often say they would like them to be better funded and resourced. **The sustainability of these services and ability to cope with an increasing demand is an important issue, and one which should be addressed by funding provided, where possible, by local authorities, Health Boards and others.**

11. INFORMATION AND ADVICE

The purpose of this chapter is to show why it is important for carers to have the right information and advice at the right time and to set out actions to improve provision in this area.

11.1 Carers frequently say that they would like the right type of information at the right time, depending on their particular circumstances. They also want up-to-date information, as sometimes they are provided with information on services that is out-of-date. Specialist health professionals can play an important role in providing condition-specific information that can help carers to understand and deal with difficult or challenging symptoms.

11.2 Carers often need assistance to navigate in and around both statutory and non statutory services and organisations.

> ***"I would like to urge other carers to get support for themselves although it was years before I realised I was a 'carer.' Never be discouraged or disheartened. If you're determined and look ahead, there is help and plenty of information out there. I have found that the National Schizophrenia Fellowship (Scotland) has been a great support and I would urge others to pluck up the courage to go to a carers' group."***
>
> This person cares for her son with schizophrenia.

11.3 **The national carer organisations and other organisations, including condition-specific organisations, provide a lot of information for carers through their publications and websites. Local carers centres have a crucial role in providing a wide range of comprehensive information and advice, including carer information packs tailored to different caring situations, benefits advice and advice on health and well-being.**

11.4 **Moreover, many other Third Sector organisations such as Alzheimer Scotland, Chest Heart and Stroke Scotland, the Stroke Association and the Parkinson's Disease Society are providing a wide range of information and advice to carers. MECOPP (Minority Ethnic Carers of Older People's Project) is the lead agency for the joint NHS 24, Health Scotland and NES**

website 'Health in my Language' which offers patients and carers access to information in community languages.

11.5 It is necessary to maintain a focus on the provision of timely, accurate and good quality information and advice not only when someone is new to caring but also whenever information and advice is needed. We have already discussed the role of healthcare and social care professionals in identifying and supporting carers and have set out actions in previous chapters. These professionals have a key role too in providing information and advice.

11.6 Moreover, the **Carers Information Zone** being established by **NHS *inform*** will have an important role in providing information to carers.

11.7 This zone, which is driven by the needs of carers, will:

- Provide a central accessible online resource of specific information for carers, ranging from practical support for looking after someone to caring for their own health and well-being; and
- Signpost carers to the most appropriate source for further information, support and guidance.

ACTION POINT 11.1
In 2010, the Scottish Government will continue to work with *NHS inform* on the development of its Carer Information Zone. Once fully developed, *NHS inform* will continually review the online service to ensure that it remains up-to-date, accurate and relevant to carers' and *young carers'* needs.

11.8 The Scottish Government launched **Care Information Scotland (CIS)** earlier this year. This service, managed by NHS 24, consists of a website service and confidential telephone helpline,[24] providing comprehensive up-to-date information on all aspects of community care for older people. CIS covers issues such as: how to get a care needs assessment; care options, including care at home and care homes; and how much care

[24] The helpline number is: 08456 001 001 and the website address is www.careinfoscotland.co.uk.

costs. CIS also provides information on local services and how to access them, and links to advice and support services. There is a 'Support for Carers' section in the website, providing general information and contact details for local services and support organisations.

11.9 CIS is available to all and is mainly being used by the friends, family and carers of older people. Carers are advised of the help available to them, in addition to the possible service options for those they care for.

11.10 As NHS 24 operates the CIS and will run the Carers Information Zone in NHS *inform*, the appropriate links are in place. Both CIS and NHS *inform* are new and will need to firmly establish the operation of their core services before considering developments. The potential for extending the services in order to provide a comprehensive helpline for all carers will be considered, along with possible alternative options.

ACTION POINT 11.2
By December 2011, the Scottish Government will gather and review the available evidence and scope the potential for a Scotland-wide carers' helpline and the options for providing it, including extending the service for carers offered by Care Information Scotland.

11.11 Many carers say that to receive information from GPs and other healthcare staff on the condition of the person they care for would help them in their caring role. They believe that they would be better equipped to care for their relative if, for example, the GP involved them in the consultation or appointment with the cared-for person.

11.12 Family members do have the right to be involved in decisions about the healthcare of people who lack capacity, balancing the patient's right to confidentiality with the principle of carer involvement. There are a number of useful sources of information on this important ethical issue, a few of which are listed below.[25]

[25] Royal College of Psychiatrists produced 'Carers and Confidentiality in Mental Health: issues involved in sharing information' http://www.rcpsych.ac.uk/PDF/Carersandconfidentiality.pdf

11.13 With regard to patients who do not lack capacity, or who do not have a mental disorder, or who are not a child, there are ethical issues about carer involvement and the right of the patient to confidentiality. No one else can make a decision on behalf of an adult who has capacity**. However, it is good practice for a GP or other healthcare professional to check whether a patient needs any additional support to understand information, to communicate their wishes or to make a decision. This may include support from a relative, partner or carer or another person close to them. There is evidence to suggest that when carers are provided with appropriate information and engaged in the care planning, the outcomes for the patient and carer are enhanced. The overriding principle is the need to consider the best interests of the patient and carer.**

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http://www.bma.org.uk/healthcare_policy/community_care/Workingwithcarers.jsp

Royal College of GPs - Confidentiality (2009) sets out the principles of confidentiality and respect for patients' privacy that doctors are expected to understand and follow. Below is link to chapter related to carers:
http://www.gmc-uk.org/guidance/ethical_guidance/confidentiality_64_66_sharing_information.asp

http://www.gmc-uk.org/guidance/good_medical_practice/relationships_with_patients_people.asp, paragraph 29

http://www.bma.org.uk/images/confidentialitytoolkitdec2009_tcm41-193140.pdf

12. CARER HEALTH and WELL-BEING

The purpose of this chapter is to set out the issues about the emotional impact of caring and the physical demands, both of which can impact adversely on carers' health. The aim is to prevent a deterioration in health as a result of caring and to promote good health, recognising that carers – like anyone else - can experience poor health unconnected with caring. Carers' health can be protected if the range of support discussed in this strategy is delivered according to individual needs. Even a sensitive and supportive carer's assessment/carer support plan can reduce stress and anxiety. This chapter also sets out plans for health checks for eligible carers.

12.1 **The emotional impact of caring for a relative or friend can be immense.** Caring, for example, for a partner or relative with dementia or other neurological conditions, or with a severe disability or long-term or fluctuating condition, or for a child with special needs, can often affect a carer's emotional well-being more than their physical health.

12.2 The major health concerns are related to stress, anxiety, emotional health and well-being generally and the physical strains of caring, especially back problems through lifting and handling. Early identification and support of carers has a positive impact on their overall health. A good service response to changed circumstances in caring is also beneficial to carers' health.

12.3 Many carers are concerned that they cannot afford to be ill, and some feel unable to continue with their caring role. Carers who do say they are able to cope often raise concerns about increasing age and their own personal health problems.

12.4 Carers can become socially isolated and ground down by trying to get services in place for the person they care for. Moreover, disability, illness, and long-term conditions often change family relationships**. Being a life-long or long-term carer is challenging.** As a caring role intensifies, many carers report how previous marital, partner or parental relationships change into patient-nurse relationships. There can be strong feelings of guilt and/or anger and an inability to cope at times.

12.5 Carers centres provide carer and peer support groups within a safe, listening environment. This is extremely valuable to many carers. With the increase in more intensive and long-lasting caring situations, there is some additional demand for professional therapeutic and counselling services.

12.6 The services and resources in place to the general population such as ***Breathing Space*** and ***Steps for Stress*** are available to carers. In addition, the Scottish Government, with partners, will produce a bespoke resource for carers on stress and caring. We acknowledge in doing so that some people will not recognise themselves as carers and may therefore use ***Steps for Stress*** only.

12.7 The new ***Wellness Recovery Action Planning (WRAP)*** promoted by the Scottish Recovery Network, who are funded by the Scottish Government, is a model with potential to help improve the mental health and well-being of the general population, including carers. The Government will work with partners to explore this further.

12.8 The Scottish Government is working closely with NHS Boards and others to expand and improve access to **psychological therapies** for people of all ages, as an alternative to drug treatments. This will benefit carers who need this type of support and who are concerned about the waiting times for such services. There is a specific commitment to enhance capacity and to train current NHS staff to deliver a range of evidence-based interventions.

12.9 **In 2010-11, the Scottish Government is developing an access target for psychological therapies (relevant to carers as part of the general population) which will complement the existing access target for those assessed as needing specialist support through the Child and Adolescent Mental Health Services (CAMHS).**

12.10 **There are other innovative approaches being taken forward at local level, such as the Carers' Counselling and Groupwork Service developed by the Voice of Carers Across Lothian (VOCAL).**

12.11 ***Information prescription*** is being taken forward in some areas in Scotland. Approved information (for example, books, DVDs, CDs and websites) can be 'prescribed' to patients and carers to enable them to learn more about the different aspects of a condition and its treatment, personal and emotional health, dealing with stress, diet and so on. These initiatives should ensure that materials are available through a wide range of distribution points, including libraries and carer support centres.

ACTION POINT 12.1
In 2011-12, the Scottish Government will continue to provide and raise awareness amongst both professionals and the general public (including carers) of *Breathing Space*. The *Steps for Stress* booklet will be available, on request.

ACTION POINT 12.2
The Scottish Government with partners, including Health Scotland and the national carer organisations, will produce a bespoke resource on issues relating to stress and caring, building on Carers Scotland publication, *Finding the Balance: Promoting Good Health – A Carers' Resource Guide to Health and Well-Being*[26] and linking in to the NHS *inform* Carers Information Zone and to *Steps for Stress.* The resource will be widely disseminated.

12.12 The **physical demands of caring** can be immense, leading to exhaustion and having an impact on emotional well-being. This is especially so where both the carer and cared-for are elderly, or where the carer is caring for someone requiring a lot of moving and handling due to limited or no mobility.

12.13 It is important for carers who are able and willing, to have training on moving and handling and on the safe use of equipment. If this is carried out in the home then the training is much more effective.

12.14 Through NHS Board Carer Information Strategies some Boards have undertaken training on moving and handling.

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26 http://www.carersscotland.org/Information/Takingcareofyourself/NewHealthResourceGuideforCarers

12.15 The Scottish Government will promote the benefits of the seasonal flu vaccine to carers. It is important for carers to protect both themselves and the people they care for from the effects of seasonal flu.

ACTION POINT 12.3
In 2010-11, the Scottish Government will encourage NHS Boards, Community Health Partnerships and local authorities to introduce programmes of training for carers on person-centred moving and handling and on the safe use of equipment. This should be linked to an assessment at the point of hospital discharge planning.

ACTION POINT 12.4
From 2010 onwards, the Scottish Government will promote to carers the benefits of the seasonal flu vaccine to help protect themselves and the people they care for.

12.16 High-risk primary prevention targeted on health inequalities is supported through the **Keep Well and Well North programmes**. These were developed to tackle health inequalities through increased investment in primary care. The programme has been targeted at those aged 45-64 living in the most deprived 15% of areas according to the Scottish Index of Multiple Deprivation (SIMD), and also at others at risk who would not be identified through this approach. The intervention involves:

- identifying and engaging with those people at particular risk of preventable serious ill-health (including those with undetected chronic disease);
- giving these people a holistic health check, which focuses on risk factors for cardiovascular disease and diabetes;
- offering appropriate interventions and services; and
- providing monitoring and follow-up.

12.17 The current target population is around 160,000, of whom around 70,000 have been checked. This will have included carers aged 45-64 living in the areas served by Keep Well.

12.18 It is not known how many carers have come forward for the health checks in the Keep Well areas. However, **NHS Scotland is**

updating its training for practitioners in the Keep Well areas, and that will include training on carer awareness and support.

12.19 The Scottish Government is also consulting on the extension of high risk primary prevention targeted on inequalities. The intention to extend the health checks include making the check five-yearly, extending to all the 15% most deprived areas and lowering the 'qualifying' age to 40 from the current 45. Health Boards are also being asked to consider how to target, reach, assess and support those at increased risk who do not live in the 15% most deprived areas, including offenders, gypsy travellers and those from BME communities. Carers will now be added to that list.

12.20 The Scottish Government sees merit in carers in the relevant age bracket having access to, and being enabled to take advantage of, these sorts of health checks, where they are also at increased risk of developing cardiovascular disease and diabetes. However, creative and flexible solutions will be required to facilitate such checks when carers cannot easily attend appointments.

12.21 The Scottish Government will also consider the evaluation, when available, of the health check pilots in England, which are underway in six demonstration areas.

ACTION POINT 12.5

In 2010-11, the Scottish Government will work with NHS Board Chief Executives to ensure the inclusion of eligible carers (ie those aged 40-64) in the list of those to be considered in the mainstreaming of Keep Well and Well North.

13. SHORT BREAKS (RESPITE)

The purpose of this chapter is to be clear about the importance of flexible, personalised short breaks provision, leading to better outcomes for carers and the people they care for. We set out actions in support of the further development and sustainability of short breaks, including the allocation of a £1 million grant to the voluntary sector.

13.1 The **terms 'short break' and 'respite'** tend to be used interchangeably. Some carers and service users prefer the term 'short break' or 'break from caring,' signifying a break from the routine.

13.2 The term 'respite', on the other hand, can imply the 'relief from a burden,' thereby giving the wrong impression of the caring relationship. It can also be associated with institutional forms of support or hospital-based stays.

13.3 Whilst many people prefer to use the term 'short break' or 'break from caring,' the term 'respite' should not be disregarded just yet as this more traditional term is still very much used and recognised. Indeed, some carers use the term themselves.

13.4 Carers say that **access to personalised, flexible short breaks** provision is crucial. Short breaks help to recharge batteries and sustain carers in their caring role. They can be a lifesaver for some. Carers can have a life of their own through the provision of suitable short breaks.

13.5 Many carers want planned breaks from caring. Carers also need to be able to mix and match different options, at different times and for different reasons. There should at all times be an emphasis on choice, flexibility and availability of break when needed.

13.6 It is also important to recognise that some groups of carers, such as BME carers, may have particular difficulties in using mainstream short break services.

13.7 Many carers do benefit from short breaks which meet their needs entirely. It gives them a good-quality break from the

stressful demands of supporting someone with a disability or long-term condition or dementia or another condition or illness. It makes life easier for the carer (and also for the person with care needs).

13.8 The break might be during the daytime or overnight. The break might be for a couple of hours or for much longer. It might involve the cared-for person having a break away from home, thus benefitting the carer in that they have time for themselves. Or the carer might have a break away, with services being put in place to support the cared-for person. Some people want to have a break together, with additional support to make this happen. Sometimes the service is provided in the home for the cared-for person, with the carer having time to do something themselves for a couple of hours during the day. This latter type of support is provided by Crossroads Caring Scotland and other organisations and by local authorities.

"We have two kinds of short breaks for our young daughter. She goes to an activity group once a week at Sense Scotland Touchbase and has great fun. She has planned overnight short breaks at Quarriers Countryview which is a big adventure for her. Both services have well-designed facilities with workers who have the expertise to support our daughter. We found out what was on offer ourselves and are delighted with the way things have worked out over the last two years. Short breaks can change as she gets older but we always want them to be enjoyable for her. We can relax knowing that she is happy."

Brett and Maggie, who care for their young daughter with a rare genetic syndrome.

13.9 The Scottish Government and COSLA recognise that there are some very good initiatives and developments at local level in the provision of short breaks. There are examples of improved consultation with carers on short breaks provision, better allocations systems resulting in improved equity of access based on assessed need, and the provision of new facilities. Some short breaks provision provides early intervention and will result in cost savings to the health and social care system.

13.10 Over the last few years there has been progress but there needs to be more – the provision of short breaks is high on the list of carers' priorities. It is not possible to know exactly how much need is unmet. This may be due in part to a lack of systematic data collection and analysis of this information. But it is also due to the fact that carers can already benefit from breaks, for example, due to a direct payment paid to the cared-for person, but with no requirement to record the break provision in any system. Carers may also benefit from voluntary sector services such as befriending provided to the cared-for person, but again this might not be known to the local authority.

13.11 Concerns about short breaks provision, include:

- Only being offered a **few hours** short break each week, with people in similar situations in other areas being provided with more hours;
- **Lack of accessible respite in rural areas,** with the respite hours being reduced because of time spent travelling to the service;

"I was very grateful to get 3 hours per week from a care provider (Crossroads) to look after my husband whilst I travelled a round trip of 68 miles to enjoy a swim or a coffee and chat with a friend."

Ann, who cares for her husband with complex health problems and limited mobility.

- Lack of suitable respite, choice and flexibility;
- Inconsistency in the approach to a needs assessment;
- Poorly managed service transitions, particularly during the transition from children's to adult services, often resulting in a loss of support at a critical time;
- Lack of involvement with carers and service users in planning and preparing for their short breaks; and
- Concerns about replacement care in times of emergency.

13.12 There are many challenging issues around the provision of short breaks. People, quite rightly, would like to be able to access a variety of short breaks provision to suit their needs.

13.13 Some provision, for example residential and overnight, is expensive to run, but some people require this. Very tough decisions are being made at local level about how best to provide and fund short breaks in light of resourcing and other pressures. The Scottish Government too, in experiencing these pressures, still aspires to take forward the Manifesto commitment of a minimum entitlement to respite for those in greatest need, but will reassess the timescale for delivery. Progress is being made with the Concordat commitment to deliver an additional 10,000 respite weeks by 2011.

13.14 In light of these challenges, **all partners need to consider how best they can support carers to have time out from caring, and develop innovative solutions based on a better understanding of people's different needs and circumstances.** For example, children with disabilities can benefit from participation in youth clubs, after-school clubs, sports clubs and holiday activity programmes.

13.15 Local authorities, with partners including NHS Boards, the voluntary sector and carers, should use their combined resources and expertise in creative ways to plan for the development of more flexible, personalised short breaks provision.

13.16 The Scottish Government received a number of good practice examples of innovative short breaks provision These included the **Short Breaks Bureau operated by Falkirk Council which benefits service users and their carers with an assessed need for short breaks. This may consist of a rolling programme of short breaks in a preferred facility, occasional breaks, or emergency placement if and when required. Falkirk Council can target service user groups, for example, mental health users, to increase the uptake by this group. North Ayrshire Council runs a short break and holiday service for people with learning disabilities, complex needs, challenging behaviour, physical disabilities or autism.** These examples and others are included in the separate Good Practice document.

13.17 Some carers whose caring responsibilities have reduced may **volunteer** by helping out in another carer's home to give them a break from caring. People who have no caring

responsibilities volunteer in this way too. This type of volunteering support is usually provided to a friend or relative.

13.18 There are also examples of volunteers supporting people they do not know initially. This type of volunteering is usually facilitated by organisations such as Volunteer Development Scotland, Community Service Volunteers and Befriending Network Scotland. The latter will launch its dementia training toolkit later this year to enable volunteers to tailor their befriending support to the needs of those with dementia and their carers.

13.19 There are differing views on whether volunteering by people who are not the carers' relative or friend, should be promoted to help provide respite. One view is that volunteers can usefully support people who do not have intensive care needs in order to allow the carer a break, whilst others believe there are issues around training, support, trust, disclosure and so on.

13.20 **The Scottish Government, Shared Care Scotland and others believe there is merit in exploring the volunteering options further as part of citizenship and community capacity building, and will build on the initial discussions we have had with a range of organisations.**

13.21 The Scottish Government has recently approved a **Public Social Partnership** pilot in part of Argyll and Bute to set up a respite bureau for carers offering a menu of respite services. The bureau will commission adult respite care services and provide a brokerage service connecting the needs of carers and service users with the menu of respite services available.

13.22 This is one of ten two-year pilot projects across Scotland seeking a new way of working between the public sector and the Third Sector. Argyll and Bute Council and Argyll and Bute Social Enterprise Network, the two partners in the project, have appointed the British Red Cross as Third Sector Partner and Preferred Provider. Shared Care Scotland is also supporting this pilot.

13.23 There are further examples of short breaks bureaus (see the Falkirk example). Shared Care Scotland has set up an Action Learning Set currently working with 9 local authorities to help take forward short break bureau developments. Ideas are shared to see if some of the administrative and funding challenges of setting

up a bureau can be tackled. The bureau helps to connect people with services that best meet their particular needs and situation.

13.24 It is very important that emergency respite care is available where, for example, a carer has to deal with an emergency and needs respite at short notice. There are various means to provide such support. **Inverclyde Council is using Concordat monies to fund the local carers' centre to provide sitter services either on a one-off or ongoing basis. This service is widely publicised in order to target 'hidden carers' as well as those already in touch with the carers centre. The Council also has a Rapid Response Team, which has a home care team to provide emergency respite.**

13.25 There are a number of Action Points as below, all relevant to ***young carers*** too:

ACTION 13.1
The Scottish Government, in allocating £1m to the national carer organisations in 2010-11 for short breaks provision, will monitor progress towards the provision of innovative, personalised, flexible provision which meets the needs of carers.

ACTION POINT 13.2
In 2010-11 the Scottish Government will work with Shared Care Scotland and others to disseminate the findings of the short breaks research and to consider the development of further actions in light of the findings. In particular, Shared Care Scotland seeks to use the research findings to support partners to improve the local strategic planning and commissioning of short break provision.

ACTION POINT 13.3
For the duration of this strategy, the Scottish Government will undertake to strengthen the NHS role as a strategic partner in supporting the provision of respite care. The Scottish Government will facilitate a high level meeting with NHS Boards to consider current practice, with a view to identifying factors which would help promote/support joint working in this area.

ACTION POINT 13.4
For the duration of this strategy, the Scottish Government with Shared Care Scotland and other partners will encourage and support the continued development of more effective ways of providing short breaks through learning networks and, where possible, the setting up of demonstration projects.

ACTION POINT 13.5
From 2011, the Scottish Government will work with a range of organisations to explore the potential to develop short breaks provision through volunteers.

ACTION 13.6
For the duration of this strategy, the Scottish Government will work with a range of organisations to explore the potential to develop emergency respite and to support carers with emergency planning.

ACTION POINT 13.7
The Scottish Government will continue to publish beyond 2011 official statistics on respite provision and will work to improve the quality and consistency of this information, in order to achieve National Statistics status for this data source and publication.

ACTION POINT 13.8
By July 2012, the Scottish Government will reassess the timescale for delivery of the Manifesto commitment to a guaranteed annual entitlement to breaks from caring for those in greatest need, taking account of progress in the delivery of short breaks through the other Action Points in this chapter.

14. CARER AND WORKFORCE TRAINING

The purpose of this chapter is to set out the positive outcomes from training provided to carers and the need for a skilled and knowledgeable health and social care workforce. Various actions are set out to help roll out carer training and to provide training to the paid workforce.

Carer Training

14.1 in recognition of the key role they play in providing care, carers should get similar opportunities for training as the paid workforce. Carers who receive training feel better supported in their caring role and more confident. Training should address the broad spectrum of the emotional impact and practical demands of caring. It should include moving and handling, managing medication, managing carers' own health and well-being, and personal development.

14.2 Consideration needs to be given to how best to meet the training needs of specific groups of carers such as BME carers.

> ***"The trainer helped me to better understand how I could deal with the difficulties I have coping with the way my son behaves because of his problems. It helped to be given some good ideas and the way these were explained in Punjabi afterwards made them easier to understand."***
>
> A Pakistani carer in Glasgow.

14.3 NHS Boards, local authorities and voluntary sector organisations need to support improved outcomes for carers achieved through carer training, including: being more positive about caring, being more confident in the caring role and having a more positive impact on the carer's health.

14.4 A lot of valuable and outcomes-focused carer training is being undertaken**. NHS Fife, with the local carers centre, has used Carer Information Strategy funding to run training sessions for carers caring for people who have had a stroke or who have chronic obstructive pulmonary disease (COPD), and for carers who care for people with autism. The Lothian carer training pilot, *Caring with Confidence*, run by NHS**

Lothian and the VOCAL Carers Centre, provided training to carers on manual handling. VOCAL has since introduced spot-purchasing of manual handling training in order to fast-track support for carers in greatest need.

14.5 There are lessons to be learned, such as having learning pathways so that carers can see the way forward to meet their knowledge, skill and support needs. One-off training is not enough in most cases. There is also some duplication of effort in the provision of training to carers, as well as gaps. More consideration needs to be given to **e-training** and to meeting the training needs of carers in **rural and remote** locations.

14.6 The Scottish Government has provided a grant of £281,000 to the national carer organisations in 2010-11 to help promote and provide carer (and workforce) training. The proposal has the following three strands:

- Carrying out a full audit of carer and workforce training provision across Scotland to get an accurate and up-to-date picture in order to enable a strategic view to be taken and to develop plans and funding requirements to address needs;
- Developing a Carer Training Consortium to support work at local level and to develop a quality assurance framework promoting high standards of training, with systematic carer outcome evaluation;
- Delivery and development of carer and workforce training by inviting applications from across the sectors, and funding carer and workforce training through the allocation of funds in a transparent way.

14.7 Subject to the outcome of the Spending Review, we will also work with NHS Boards so that they will make a carer training offer to carers.

ACTION POINT 14.1
The National Carers Organisations will use the £281,000 grant from the Scottish Government to allocate grants to a range of organisations for carer and workforce training in a transparent and outcome-focused way. The NCOs will ensure dovetailing with the NHS Board Carer Information Strategies.

ACTION POINT 14.2
NHS Boards will build on the carer training provided under the Carer Information Strategies and continue to train carers beyond 2011. Subject to the outcome of the Spending Review, the Scottish Government will also work with NHS Boards so that they will make a training offer to carers.

Workforce Training

14.8 A well-informed, knowledgeable, trained and skilled health and social care workforce is essential to help improve the lives of carers and young carers.

14.9 Health and social care staff should have a proper appreciation of the role of carers and ***young carers*** and commit to engage with carers as equal and expert partners in the design and delivery of health and social care services.

14.10 NHS Boards and local authorities need to continue to take forward workforce training through induction training and continuous professional development. **Relevant good practice includes Glasgow City Council's mandatory training module for health and social work staff and NHS Lothian's e-training for the workforce.**

14.11 The Scottish Government will take forward workforce training issues with the Scottish Social Services Council (SSSC), with NHS Education for Scotland (NES) and with others.

14.12 The national carer organisations will be using part of the £281,000 grant from the Scottish Government to allocate grants in 2010-11 to a range of organisations for workforce training. The NCOs will ensure dovetailing with all other workforce training, including that being taken forward by NHS Boards.

ACTION POINT 14.3
In 2010-12, NHS Education for Scotland (NES), in collaboration with NHS Boards and the national carer organisations, will review existing training, education and learning modules for working with carers and *young carers;* identify core competencies for NHS staff in identifying and supporting carers and *young carers;* and identify packages and materials to be incorporated within core induction, education and training curricula.

ACTION POINT 14.4
NES will communicate to the relevant regulatory, professional and national bodies the importance of identifying and supporting carers and *young carers* in workforce training and education.

ACTION POINT 14.5
From 2010 onwards, the Scottish Government will work with NHS Boards to ensure that identifying and supporting carers and *young carers* is embedded in workforce training.

ACTION POINT 14.6
From 2010 onwards, the Scottish Government will continue to promote the benefits of workforce training through the Scottish Social Services Council (SSSC), the national carer organisations and others.

ACTION POINT 14.7
In 2011-12, NHS Education for Scotland (NES), and the national carer organisations will produce a good practice guide to workforce training. This will be widely distributed.

15. HOUSING AND HOUSING SUPPORT

The purpose of this chapter is to indicate the importance to carers of having suitable housing and to set the necessary action within the context of housing reform and Reshaping Care.

15.1 There is no specific Care 21 recommendation in relation to housing or housing support. However, over the past few years carers have raised a number of concerns about housing, primarily the suitability of housing for changing needs, and housing for adults with learning disabilities who outlive their parents. Issues about equipment and adaptations are covered in chapter 16 on the use of assistive technology. However, it is important to note here that aids and adaptations can help people to remain in their own home which can result in less pressure on social housing.

15.2 Some of the specific concerns raised include:

- People with learning disabilities can be allocated a house but then there is no funding to put the support services in place. We should explore ways of predicting demand (for housing and support) that link person-centred planning with capacity;
- Houses are in the wrong location for individuals;
- People with learning disabilities want and should be able to access the same opportunities for having their own home as people without disabilities;
- Much of sheltered housing is single room or bedsit and does not allow for visiting carers and other family members, and supported accommodation does not allow for partners to be resident and to continue in their caring role; and
- Equipment and adaptations should be provided quickly (see chapter 16 on Assistive Technology).

15.3 Housing is an important element in enabling carers to support the person they care for to live independently, safely and with dignity in their own homes and communities.

15.4 The issues raised by carers have been recognised as part of the joint Scottish Government/COSLA Reshaping Care programme. The housing workstream known as 'Wider Planning for an Ageing Population' has been taken forward through a stakeholder working group. The group has identified five main outcomes for older people's housing:

- Clear strategic leadership is in place at national and local level about the housing outcomes to be delivered for older people;
- Older people are better assisted to remain in, and make best use of, existing housing stock;
- Investment in new housing provision across the sectors meets the future needs of older people;
- The needs of older people for low level, preventative support are met; and
- The infrastructure to support these outcomes is improved.

15.5 The workstream also considered a range of options to achieve these outcomes. Its report[27] proposes 27 suggested actions for specific measures, covering policy, evidence, standards, guidance, delivery and infrastructure.

15.6 The Scottish Government has launched a discussion paper on the future shape of housing policy in the light of the action taken to respond to the economic downturn, the future constraints on public expenditure, and the many other challenges facing Scottish housing over the next few years. One of these is responding to the increase in the number of people aged 75 and over. The discussion paper therefore highlights the importance of supporting independent living, and more effective links between housing, social care and health policies and services in the future. This should assist those caring for older or disabled people.

15.7 **Glasgow City Council has recently demonstrated how allocations policies can be adapted to support families in difficult circumstances. With a range of partners the Council produced in March 2010 '*A Practical Guide for Registered Social Landlords: Housing and Autism Spectrum Disorder (ASD).*' These guidelines are a reminder of what registered social landlords need to do to fulfil their duties and to assist people with ASD to get access to appropriate living conditions. It is helpful to the carers of people with ASD. For example, a single mother of two children, one with Asperger's Syndrome, lived in a two-bedroom property in multi-storey flats. The son with Asperger's Syndrome needed his own**

[27] http://www.jitscotland.org.uk/action-areas/reshaping-care-for-older-people/workstream-e---wider-planning-for-an-ageing-population---housing-and-communities/

bedroom. The allocations policy did not take account of her son's need for his own space, as it only took account of physical disability. The Autism Resource Centre worked closely with the Registered Social Landlord to amend the policy so as to award a medical priority for applicants affected by ASD.

ACTION POINT 15.1

For the duration of this strategy, the Scottish Government and COSLA will work with local authorities, housing associations, the independent rented sector, Health Boards and other partners to ensure that the needs and views of carers are taken into account in developing more effective links between housing, social care and health policies and services.

ACTION POINT 15.2

Carers views will be taken into account during public engagement events in 2010 on the Reshaping Care for Older People programme. These views will help shape the development of that programme.

16. USE OF ASSISTIVE TECHNOLOGY

The purpose of this chapter is to set out action to extend the use of telecare and to ensure that carers have access to information and training on the use of equipment.

Telecare

16.1 **Telecare** is the remote or enhanced delivery of care services to people in their own home or a community setting by means of telecommunications and computerised services. The term usually refers to sensors and alerts which provide automatic and remote monitoring of care emergencies and lifestyle changes, to trigger human responses or shut down equipment to prevent hazards. All 32 local partnerships in Scotland have developed telecare services.

16.2 A very broad range of technologies to support health and care needs has been developed. The term 'telehealthcare' is now being used to describe the wider package of services.

Case study

Joyce has dementia and lives with her husband in Edinburgh. Joyce tends to walk about during the night. Recently Joyce was admitted to hospital, unlikely to return home due to her health situation and lack of management of her night walking. However, Joyce was provided with a telecare solution, including a property exit sensor and a pager system. Should Joyce try to leave the house during the night, the property exit sensor automatically raises a call to her husband's pager and gradually turns on the bedside light. This allows Joyce's husband to get to the front door or street to assist his wife to return home. It also helps him to get a better sleep knowing he will be alerted if needed.

16.3 In an independent review of the Telecare Programme in 2008,[28] 74% of carers reported reduced stress and 93% of those being cared for felt safer at home. More recent research[29] further

[28] The York Health Economics Consortium (YHEC)
[29] A Weight off My Mind – Exploring the Impact and Potential Benefits of Telecare for Unpaid Carers in Scotland, December 2009

reinforces these findings, and identifies that carers can benefit significantly from using telecare services.

16.4 Carers have said:

"When you have a vulnerable person to care for in your house, it feels like you're on duty 24/7. So it was wonderful, it allowed me to relax, gave me chill out time. I wasn't on alert throughout the night."

"I can sleep easier and work easier knowing that a call-out will happen if something is wrong."

16.5 The appropriate and targeted use of telecare can help carers by: providing affordable access to support and assistance round the clock; supporting individual, personalised services; achieving fewer days in hospital and care homes and less Accident and Emergency admissions; reducing stress and providing peace of mind; enabling a good night's sleep; helping some carers to combine work and care; providing some with an opportunity for a life outside of caring; and providing early intervention.

16.6 The Scottish Government will work with partners, including local authorities, to ensure that telecare fully benefits carers in Scotland, enables more people to live independently and improves the quality of life for carers.

ACTION POINT 16.1
In 2010-11 the Scottish Government, with local authority and other partners, will raise awareness of telecare amongst carers nationally and locally and will ensure that carers have better access to appropriate information on services.

ACTION POINT 16.2
The Scottish Government, with Carers Scotland, will ensure that carers' training is included as part of a national approach to telecare education and training, with a specific workstream developed to address this over 2010-12.

ACTION POINT 16.3
In 2010-12, the Scottish Government will ensure that telecare is included in the practical guide to undertaking carers' assessments and will promote its further integration within Single Assessment and Care Management/Review protocols and processes.

ACTION POINT 16.4
By 2015, the Scottish Government will further maximise the impact of its telecare investment to ensure that the benefits and applications of the new technology for carers continues and develops.

ACTION POINT 16.5
In 2010-2015 the Scottish Government will further explore the innovative use of new technologies in support of carers living in remote and rural areas, and identify mechanisms which may be more accessible to *young carers.*

Equipment and Adaptations

16.7 Equipment and adaptations can play an important part in supporting the role of carers. Having the right equipment or adaptations in the home will allow the cared-for person to remain at home for longer. It will also reduce the pressure on, and risks to, the carer and it can help prevent hospital admissions.

16.8 Research[30] has shown that many carers and other family members are putting their health at risk, or suffering actual short or long-term injury, through lifting or carrying their children or other relatives, because of the lack of suitable facilities.

"His mother had back problems and had to have an emergency operation after lifting him onto the toilet one day. She has seen X-rays of her spine which have convinced her that she cannot risk further damage by trying to help him in these areas."

16.9 It is clear that the provision of equipment and adaptations can provide physical relief, particularly with regard to back strain.

[30] Money Well Spent: The effectiveness and value of housing adaptations. Joseph Rowntree Foundation 2001

There are also financial and economic implications, as a damaged back can cost the state in medical treatment and lost employment.

16.10 The issue of compatibility of equipment is often raised by carers, including parent carers, young people and practitioners. Parents in particular feel that manufacturers should work together to ensure equipment is compatible.

16.11 Any unnecessary delay in the provision of equipment and adaptations can cause frustration and put carers and the people they care for at risk.

16.12 **It is essential therefore that assessments are carried out as early as possible and that the views and experience of the carer are taken into account. The assessment should take into account how needs will change over time, especially when providing adaptations. Where delays are unavoidable, carers and the people they care for need to be kept informed, advised of the reasons for any delay and given a realistic timescale for delivery of equipment or completion of the adaptation.**

16.13 It is also vital that **carers receive adequate training** on the use of the equipment provided. The Handle with Care Report[31] published in 2008 by Scotland's Commissioner for Children and Young People highlighted this as a major issue.

16.14 The report stated that the vast majority of the parents and carers had received no moving and handling training. One carer stated:

"We never get offered moving and handling training. Our hoist was put in at home but no training was offered regarding the hoists and slings. They didn't even guide us to where we could get training."

[31] Handle With Care: A Report on the Moving and Handling of Children and Young People with Disabilities. SCCYP 2008

ACTION POINT 16.6
In 2011-15 the Scottish Government, with local authorities, Health Boards and other partners, will raise awareness of equipment and adaptations amongst carers and ensure that carers have better access to appropriate information and training on equipment.

17. ADVOCACY SUPPORT

The purpose of this chapter is to confirm the importance and value of advocacy for carers in their own right and to encourage support for the development of carer advocacy.

17.1 Three dedicated carer advocacy initiatives operate in Scotland. Carer advocacy provides an important support to the most vulnerable carers to help them to communicate their views clearly and to support them on complex issues relating to the caring situation. Often these can require the co-ordination of action by several agencies or cover situations where carers seek to access mainstream provision for people with support needs. There may be situations where persistence is required over a long period of time to reach a solution, for example, with housing issues such as relocation or major housing adaptations to provide for independent living.

17.2 In addition to their caring responsibilities, carers can be swamped by a large volume of paperwork from a range of agencies involved with the care of the service user. They may also be required to produce a significant amount of correspondence themselves. Carer advocacy services support carers to fill in various forms and applications, write appeal submissions, draft formal complaint letters, write specialist education placement requests and write to MSPs, MPs and councillors.

17.3 Carer advocacy organisations report positive outcomes for carers on a wide range of issues, for instance, one-off interventions, multi-disciplinary hearings and long campaigns for re-housing or housing extensions to accommodate people with complex disabilities. Many of the beneficiaries are themselves disabled or elderly, or have mental health problems or learning disabilities. Providing carer advocacy can help restore family and partner relationships.

17.4 Carer advocacy should not generally be provided by independent advocacy workers who also represent users of services, as this may lead to a conflict of interest and undermine national guidance on principles and standards of advocacy. Carers centres are well placed to provide carer advocacy as most local carer organisations already fulfil the role as collective carer advocacy organisations.

"I am the sole carer for my son who has Autistic Spectrum Disorder. His condition was not diagnosed and he was excluded from school for nearly 4 years. I was judged by many professionals to be the cause of his behaviour. He was violent and abusive towards me and I became depressed and suicidal. Having been informed of the existence of the local Advocacy Service I now have a trained and sympathetic advocate who has, after a 3 year battle, got my son diagnosed and starting to be integrated into mainstream education. Advocacy has been my lifeline. I can rely on her support and advice at any time. She is both mine and my son's voice at meetings."

Allison, who is the sole carer for her son, who has Autistic Spectrum Disorder.

17.5 The Scottish Government and COSLA recognise the value and benefit of representation for carers and will consider the scope for guidance about carer advocacy. In view of the fact that the most vulnerable carers can benefit enormously from advocacy support relating to their ability to care and the support they receive for their caring role, we will also encourage local partners to develop or expand carer advocacy.

ACTION POINT 17.1
The Scottish Government and COSLA acknowledge the value and benefit of carer advocacy. From 2011 onwards we will encourage local authorities, NHS Boards and other local partners to develop or expand carer advocacy services for those in greatest need. We will also in 2011-12 examine the scope for producing guidelines on carer advocacy.

18. EMPLOYMENT AND SKILLS

The purpose of this chapter is to confirm the importance of carer employment, skills development and lifelong learning, recognising the important role of carer-friendly and flexible working practices and to set out actions in support of this.

18.1 Taking on a caring role should not mean that people have to give up work to care. If people have to leave paid employment, reduce hours of work or move into a lower skilled job, they can experience financial hardship through loss of earnings (estimated at £11,822 each year[32]) and pension rights.

18.2 The benefits of employment to individuals in society (for example, income, responsibility and respect) should extend to carers. Carers who want and are able to work should be enabled to do so, and should not be discriminated against. They should be supported in the workplace to maintain their employment status.

18.3 The particular challenges faced by BME carers whose communities are characterised by very high levels of self employment, (for example, retail and catering) need to be tackled so that BME carers are not excluded from employment opportunities.

18.4 Carers should have access to lifelong learning opportunities, further and higher education and skills development in ways which take account of their caring responsibilities.

18.5 There is a good economic and business case for supporting carers through introducing and extending flexible working practices.[33]

18.6 Employment is reserved to the UK Parliament. However, the Scottish Government, through skills development and economic policies, and the promotion of carer-friendly working practices, can support carers to remain in, or return to, employment or to take up lifelong learning opportunities. Where working age carers have to give up employment to care, there needs to be access to ongoing support.

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[32] Out of Pocket, Carers UK, 2007

[33] Who Cares Wins: The Social and Business Benefits of Supporting Working Carers, 2006, Bucker L and Yendle S, Carers UK

18.7 It is important to support carers as they begin to plan their route back into work or learning once caring ends.

18.8 The JobCentre Plus programme in Scotland, Work Focused Support for Carers, is in place.

18.9 Many employers have developed carer-friendly policies and effective workplace practices, enabling carers to remain in, or to return to, work.[34]

18.10 There is a clear message and vision in the Skills for Scotland Strategy and the Scottish Government's economic policies that we have the potential to do more with the skills available to us. The refreshed Skills Strategy for Scotland will emphasise the importance of skills development for carers and ***young carers*** and the skills that carers and young carers bring to employment.

18.11 The Scottish Government is pleased that Skills Development Scotland[35] has undertaken to support carers and young carers in both the short and longer term. Skills Development Scotland has committed to a number of Action Points. Those in relation to ***young carers*** are included in the young carers' part of the strategy.

[34] National Framework for Carers and Employment, Carers Scotland (2007)
[35] Set up in 2007, Skills Development Scotland is a non-departmental public body, accountable to Scottish Ministers

ACTION POINT 18 1
In 2010 and beyond, the Scottish Government will:
- encourage public bodies,[36] through identifying and building on good practice, to promote carer friendly employment practices;
- identify ways in which the Scottish Government can work with employers and others to promote carer friendly employment practices. The Scottish Government's Employability Learning Network (ELN) will help with this, including consultation with employability stakeholders.

ACTION POINT 18 2
By September 2011, Skills Development Scotland will increase awareness of its services and resources with carers' centres in Scotland, facilitated by the PRTC.

ACTION POINT 18.3
By December 2011, Skills Development Scotland will explore the opportunities afforded to carers by its partnership with JobCentre Plus, to develop an Integrated Employment and Skills service.

ACTION POINT 18.4
By March 2012, Skills Development Scotland (SDS), the national carer organisations and the network of carers centres will work together to build on good practice to:
- identify the learning, career aspirations and employability requirements of carers;
- identify ways in which SDS services can be more effectively targeted to help carers into training and employment.

[36] Executive Non Departmental Public Bodies (NDPBs), Advisory NDPBs, Tribunals, NHS Bodies and other significant national bodies

19. TACKLING POVERTY: FINANCIAL INCLUSION

The purpose of this chapter is to summarise the issues which have an impact on carers' level of income and to set out actions to help carers maximise their income. Policy on, and administration of, all benefits and tax credits, including the Carer's Allowance, is the responsibility of the UK Government.

19.1 Poverty and worries about finances can have an adverse impact on carers' health, wellbeing and quality of life.

19.2 A wide range of issues impacts on carers' level of income. Carers can experience significant financial hardship as a consequence of their caring role. They are often faced with additional costs, including fuel costs,[37] as a result of the illness or disability of the person they care for, and their caring responsibilities can act as a barrier to entering paid employment.

"Because the house is used 24/7, gas and electricity consumption is higher than for those who go out to work. I estimate at least double that of working people."

19.3 Many carers, both those aged over 60 and younger carers, do not claim the full range of benefits to which they are entitled. They miss out on pension credits, the Carer's Allowance and other benefits.[38]

19.4 While the Scottish Government does not have responsibility for the welfare system, it does have some important levers to influence the uptake of benefits. It has made clear statements about the importance of the benefit and tax credit system working in partnership with local welfare rights information and advice services to maximise income and promote financial capability. The Scottish Government and COSLA framework for tackling poverty and income inequality, *Achieving our Potential,*[39] sets out the wider approach to addressing poverty and disadvantage.

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[37] Carers in Crisis (2008), Carers Scotland and Carers UK
[38] Caring and Pensioner Poverty: A Report on Older Carers, Employment and Benefits (2005), Carers UK; Carers' Missing Millions (2003), Carers UK; Carers in Crisis (2008)
[39] http://www.scotland.gov.uk/Publications/2008/11/20103815/0

19.5 **Income maximisation support is vital at points of transition in people's lives, and should be integrated with holistic services that address all aspects of financial and social exclusion and health and wellbeing. It is important to ensure that people claim all of the financial support to which they are entitled but the work on income maximisation is wider than that. It includes reducing expenditure by, for example, providing advice on the best fuel tariffs or on home insulation, or helping people to manage their debts. It involves a wide range of partners in addition to the named agency.**

19.6 A range of support exists to help those with caring responsibilities to access all of the benefits, tax credits and grants that they are entitled to. Welfare rights services are central to local citizens advice bureaux. Many other locally-based services also focus on those communities and households which are most vulnerable to poor outcomes. **Increasingly, Community Planning Partnerships are enhancing established mainstream services to provide holistic and responsive care which addresses all aspects of life circumstances, such as income maximisation, debt advice, access to affordable credit and supporting financial capability. The Scottish Government plans to explore the role of Single Shared Assessments in ensuring that carers are aware of, and receiving all of, the benefits and tax credits to which they are entitled, and in referring individuals for benefit checks where appropriate.**

19.7 Arrangements for supporting financial capability locally vary across the country, with services provided by, amongst others, local authorities, community and voluntary groups, credit unions and Citizens Advice Bureaux. Nationwide services are provided by helplines such as Citizens Advice Direct, Care Information Scotland and the National Debtline. The Consumer Financial Education Body's service, *Moneymadeclear*, offers information and guidance on financial matters, tailored to an individual's needs and circumstances. It is a proactive, early intervention service aiming to help people make confident, informed decisions and make the most of their money, without trying to sell them financial products.

19.8 *Moneymadeclear* is available on the phone, on the web and currently face-to-face in the Glasgow area. **The face-to-face**

service will be available across Scotland from the end of 2010[40].

19.9 Intermediaries that deliver advice and support to carers are encouraged to access training which increases the capacity of frontline agencies to provide accurate, high quality and effective advice and information on tax credits and other welfare benefits to eligible claimants. This will help maximise the potential income available to families and individuals. The Child Poverty Action Group Second Tier Advice Project delivers such training, funded by the Scottish Government[41].

19.10 Since April 2009, income maximisation checks have been undertaken as part of the Energy Assistance Package. These are carried out by the Pensions Service for people aged 60 and over, and by Citizens Advice Direct for those aged under 60. **Appendix 9** provides background on the Energy Assistance Package.

19.11 Carer organisations, other Third Sector and statutory bodies should continue to raise awareness of the benefits to which carers, and those they care for, may be entitled to.

ACTION POINT 19.1
The Scottish Government will pursue with the new UK Government, as it did with the previous administration, the level of the Carer's Allowance and a review of financial support to carers.

ACTION POINT 19.2
The Scottish Government will work with local authorities and the NHS to enhance the role of Single Shared Assessments and Carers Assessments (Carer Support Plans) as opportunities to promote financial inclusion for carers.

19.12 Carers can be concerned about local authority charging policies for a range of social care services and supports. They cite a range of issues, including lack of consultation on increased

[40] More information is available at: http://www.moneymadeclear.fsa.gov.uk/
[41] http://www.cpag.org.uk/scotland/

charging, sharp means testing tapers on respite charges and differences in approach in different areas.

19.13 Local authorities will continue to charge service users and carers for services and support. However, COSLA promotes the use of consistent and transparent charging policies across the country and refreshes its charging guidance on an annual basis. **COSLA is also moving to an online facility, whereby every council's charging policy will be available to view online. A benchmarking facility is also planned for practitioners in local authorities in order to achieve consistency in the way charging policies are formulated.**

ACTION POINT 19.3
COSLA will create a benchmarking network to facilitate consistent approaches to charging for non-residential social care services across local authorities. Work will be undertaken annually to assess levels of consistency across Scotland. As part of this process COSLA will engage with national carers organisations to listen and respond to any concerns.

Appendix 1

Membership of Carers Strategy Steering Group

Name	Organisation
Pat Begley	Carers Scotland
Sue Brace	City of Edinburgh Council/ADSW
Florence Burke	Princess Royal Trust for Carers (PRTC)
Claire Cairns	Coalition of Carers in Scotland (COCIS)
Fiona Collie	Carers Scotland
Anne Conlin	Carers Scotland
Sam Coope	Scottish Government
Ron Culley	COSLA
Sharon Duncan	NHS Grampian
Sebastian Fischer	COCIS and Voice of Carers Across Lothian (VOCAL)
Lorna Kelly	NHS Greater Glasgow and Clyde
Suzanne Munday	Minority Ethnic Carers of Older People Project (MECOPP)
Moira Oliphant	Scottish Government
Catherine Paterson	Carers Reference Group
Gordon Paterson	Scottish Government (seconded from Fife Council)
Adam Rennie	Scottish Government (Chair)
Julie Rintoul	Scottish Government
Fiona Roberts	Alzheimer Scotland
Jack Ryan	Crossroads Caring Scotland
Martha Shortreed	Social Work Inspection Agency (SWIA)
Julie Webster	Scottish Government (Minutes)
Lynn Williams	PRTC
Don Williamson	Shared Care Scotland

Appendix 2

Membership of Carers Reference Group

NAME	AREA	CARING SITUATION
Tony Fitzpatrick (resigned)	North Lanarkshire	Adult daughter with severe learning difficulties
Alan Gow	Glasgow	Adult son with mental health problems
Anne Henderson (resigned)	Highland	Dual caring role
Rosemary Kennedy	Glasgow	Mother with dementia, who sadly died
Anne Macleod	Edinburgh	Adult daughter with complex disabilities as a result of Rett Syndrome
Brett Millett	Glasgow	Young daughter with rare genetic syndrome, Cornelia De Lange Syndrome
Ann Oliver	Highland	Husband who has complex health needs, including limited mobility and bone structure problems
Catherine Paterson	Argyll and Bute	Former carer for husband with motor neuron disease. Now caring for parents in their 80s, one with dementia
Eleanor Robertson	Renfrewshire	Adult son with drug addiction since age 17
Samar Sheikh	Lanarkshire	Adult son with disabilities (similar to cerebral palsy)
Paul Weddell	West Lothian	Wife has multiple sclerosis and adult daughter has learning difficulties

Appendix 3

Action Points and Implementation Plan

All Action Points are relevant to ensuring better outcomes for carers as follows: Carers will:

- **Have improved emotional and physical well-being.**
- **Have increased carer confidence in managing the caring role.**
- **Have the ability to combine caring responsibilities with work, social, leisure and learning opportunities and retain a life outside of caring.**
- **Not experience disadvantage or discrimination, including financial hardship, as a result of caring.**
- **Be involved in planning and shaping the services required for the service user and the support for themselves.**

1.	ACTION POINTS AND IMPLEMENTATION PLAN	IMPLEMENTATION LEAD
1.1	The Scottish Government. with COSLA, will keep this strategy under review. An Implementation and Monitoring Group will report annually on progress with the first report being undertaken by August 2011. A formal review will be concluded by August 2013. As part of the review the Scottish Government, with COSLA, and informed by the views of stakeholders, including carers, will decide whether new or revised actions would be appropriate.	Scottish Government and COSLA - with partners
2.	**INTRODUCTION**	
2.1	Councils, with partners in NHS Boards, the national carer organisations and other Third Sector organisations, will continue to promote personalisation, working towards a position whereby staff at all levels receive induction training and continuous professional development on this approach,	Councils - with Health Boards, NCOs and other Third Sector

	including having specific regard to the personalisation of carers' support (also see chapter 14 on training).	organisations
2.2	The Scottish Government will publish on its website each year the baseline position on respite support to carers and the position in all years up to 2015.	Scottish Government
2.3	Each year, participating local partnerships will collect the relevant data on outcome measures relating to carers in the Community Care Outcomes Framework and will publish progress against the three outcome measures.	Local Community Care Partnerships - with Community Care Benchmarking Network
2.4	Over the next 5 years, councils and Health Boards, with partners, will take account of good practice promoted in local authority and Health Board areas and will consider how the good practice can be transferred, if appropriate, and/or will consider whether or how existing services and supports can best be reconfigured to achieve the best outcomes for carers and for those they care for. As a first step, councils and Health Boards, with partners, will consider the good practice contained in the publication accompanying this strategy.	Councils and Health Boards - with partners
2.5	By 2015, the Scottish Government will ensure that the intentions to accelerate the pace of sharing good practice under Reshaping Care take account of good practice in supporting carers.	Scottish Government
3.	**PROFILE OF CARERS**	
3.1	The Scottish Government will make the information collected on carers ***and young carers*** through surveys such as the Scottish Household Survey and Scottish Health Survey accessible to researchers, care providers and the public through its website and publications.	Scottish Government - with local authorities
3.2	In respect of the 2011 Census, the views of carers' organisations will be taken into account in deciding what analysis tables will be produced for the General Register Office for Scotland 2011 Census website.	Scottish Government - with GRO(s)
3.3	In 2011-12, the Scottish Government will draw up a specification and seek to commission research on communities of carers we know little about including refugees, asylum seekers, gypsy travellers and carers with disabilities, including learning disabilities. ***(Relevant to young carers too).***	Scottish Government - with NCOs
4.	**PRIORITISING SUPPORT FOR CARERS**	
4.1	By 2012, if they have not already done so, local authorities with partners, will wish to revisit their local carer strategies to identify and support carers in need according to their own assessment of need.	Councils Scottish Government

	To support this process, the Scottish Government will produce a short list of key points that local carer strategies should address.	
42	By 2013, local authorities, with partners, will aim to identify carers in greatest need according to an objective assessment of need, and in line with published indicators, which also takes account of the nature and level of risk. They will aim to provide support, or signpost on to support.	Councils
4.3	Over the next five years, local authorities and Health Boards, with partners, should seek to provide preventative support to carers and minimise the need for crisis intervention.	Councils and Health Boards
4.4	Over the next 5 years the Reshaping Older People's Care Programme will look to ensure a focus on early intervention for carers. Good practice in this area will be transferred to other care settings.	Scottish Government - with partners
5.	**EQUALITIES – EQUALITY GROUPS AND CARING IN REMOTE AND RURAL AREAS**	
5.1	The Scottish Government, with COSLA and partners, will ensure that all the Action Points in this strategy are taken forward in ways which fully address the equalities perspective.	Scottish Government and COSLA - with partners
5.2	From 2010 onwards, the Scottish Government will work with the relevant local authorities, Health Boards and Third Sector organisations to develop plans to help address rural carer issues.	Scottish Government - with councils and Health Boards and other partners
6.	**CARERS RIGHTS**	
6.1	From 2010 onwards, the Scottish Government will work with the national carer organisations to promote the Equality Act 2010, once commenced, especially the provisions providing protection from discrimination for carers.	Scottish Government - with NCOs
6.2	The Scottish Government will work with COSLA and local authorities to ensure a consistent approach across local authorities to the employment of close family members in exceptional circumstances. The guidance on implementation of the Self-Directed Support Strategy, to be produced by the Scottish Government, will include a section on approaches to the employment of close family members in exceptional circumstances.	Scottish Government and COSLA - with councils
6.3	By December 2011, the Scottish Government will produce, with COSLA and partners, a Carers Rights Charter for wide distribution to local authorities, Health Boards, Community Health Partnerships and other bodies. By December 2013, the Scottish Government will consider whether further rights should be enshrined in law.	Scottish Government - with councils, NHS Boards, NCOs and other partners

7.	**CARER INVOLVEMENT IN PLANNING, SHAPING AND DELIVERY OF SERVICES AND SUPPORT**	
7.1	In 2010-11, the Scottish Government will ensure carer representation on CHPs by writing to the Chief Executives of Health Boards to make this happen.	Scottish Government
7.2	In 2010-11, in taking forward a review of Public Partnership Forums, the Scottish Government will ensure that it consults with appropriate carer organisations in order that their interests are fully represented.	Scottish Government
7.3	Local authorities and NHS Boards will ensure they fully involve the national carer organisations, other Third Sector organisations and carers, as appropriate in the planning and shaping of services and support.	Councils NHS Boards - with partners
7.4	In 2010 and beyond, the Scottish Government and COSLA will promote the Social Care Procurement Guidance to local authorities so that they are aware of that part of the guidance on carer participation and can act on it as appropriate. Furthermore, the Scottish Government will provide training for procurement staff, establish learning networks, and promote good practice to continue to seek improvement in procurement practices across Scotland, which will take account of the need to involve carers.	Scottish Government COSLA
8.	**IDENTIFICATION OF CARERS**	
8.1	From 2010 onwards, the Scottish Government will promote this strategy with Alcohol and Drug Partnerships (ADPs) and with the Scottish Drugs Recovery Consortium (SDRC) and will work with ADPs and with the SDRC to help identify and support carers of people with substance misuse problems.	Scottish Government - with ADPs and SDRC
8.2	The Scottish Government will approach all relevant national training and qualification accreditation bodies to agree how they could integrate carer identification and awareness into the curriculum by 2013.	Scottish Government
8.3	In 2011-12 and beyond, local authorities, Health Boards and all carer support organisations are to identify carers and ***young carers*** in the hard-to-reach groups, including BME carers.	Councils Health Boards Carer Support Organisations
8.4	In 2010-11, the Scottish Government will work with the Royal College of General Practitioners	Scottish Government

	Scotland on its plans to provide guidance to GP practices in Scotland on carer ***and young carer identification and support.***	- with RCGPS and NCOs
9.	**CARERS ASSESSMENTS (CARER SUPPORT PLANS)**	
9.1	On an ongoing basis, in order to fully engage carers and deliver improved outcomes for carers, the Scottish Government will continue to promote and monitor the use of carer outcome evaluations through *Talking Points.*	Scottish Government
9.2	On an ongoing basis, in order to improve the knowledge and skills of the social care and health workforce in undertaking carers' assessments, the Scottish Government, in partnership with local authorities, will continue to encourage and promote the further training and development of staff. (Also refer to chapter 14 on training).	Scottish Government - with local authorities
9.3	In order to improve the carrying out of carers' assessments with the aim of delivering improved carer support, the Scottish Government will, by 2012, commission the production of practical guidance on the undertaking of carers' assessments. This will include guidance on how to conduct culturally competent assessments. This will be done in partnership with COSLA and NHS Scotland and will be informed by stakeholders and carers.	Scottish Government - with COSLA and NHS Scotland and other partners
9.4	On an ongoing basis, local authorities will monitor the impact and outcomes of carers' assessments. If any resources, supports and services are not available to meet need, local authorities will use the carer assessment process (and other initiatives) to record what is currently unavailable. This will assist strategic planning with respect to carers' support.	Local authorities
10.	**RANGE AND TYPE OF SUPPORT – NO ACTION POINTS IN CHAPTER 10**	
11.	**INFORMATION AND ADVICE**	
11.1	In 2010, the Scottish Government will continue to work with *NHS inform* on the development of its Carer Information Zone. Once fully developed, *NHS inform* will continually review the online service to ensure that it remains up-to-date, accurate and relevant to carers' and ***young carers'*** needs.	*NHS inform* Scottish Government
11.2	By December 2011 the Scottish Government will gather and review the available evidence and scope the potential for a Scotland-wide carers' helpline and the options for providing it, including extending the service for carers offered by Care Information Scotland.	Scottish Government
12.	**CARER HEALTH and WELL-BEING**	
12.1	In 2011-12, the Scottish Government will continue to provide and raise awareness amongst both	Scottish Government

	professionals and the general public (including carers) of *Breathing Space.* The Steps for Stress booklet will be available on request	
12.2	The Scottish Government with partners, including Health Scotland and the NCOs, will produce a bespoke resource on issues relating to stress and caring, including building on Carers Scotland publication, *Finding the Balance: Promoting Good Health – A Carers' Resource Guide to Health and Well-Being* and linking in to the NHS *inform* Carers Information Zone and to *Steps for Stress*. The resource will be widely disseminated.	Scottish Government - with Health Scotland and the NCOs
12.3	In 2010-11, the Scottish Government will encourage NHS Boards, Community Health Partnerships and local authorities to introduce programmes of training for carers on person-centred moving and handling and on the safe use of equipment. This should be linked to an assessment at the point of hospital discharge planning.	Scottish Government NHS Boards CHPs Councils
12.4	From 2010 onwards, the Scottish Government will promote to carers the benefits of the seasonal flu vaccine to help protect themselves and the people they care for.	Scottish Government
12.5	In 2010-11, the Scottish Government will work with NHS Board Chief Executives to ensure the inclusion of eligible carers (ie those aged 40-64) in the list of those to be considered in the mainstreaming of Keep Well and Well North.	Scottish Government
13.	**SHORT BREAKS (RESPITE) *(all relevant to young carers)***	
13.1	The Scottish Government, in allocating £1 million to the national carer organisations in 2010-11 for short breaks provision, will monitor progress towards the provision of innovative, personalised, flexible provision which meets the needs of carers.	Scottish Government - with NCOs
13.2	In 2010-11 the Scottish Government will work with Shared Care Scotland and others to disseminate the findings of the short breaks research and to consider the development of further actions in light of the findings. In particular, the research findings will be used to support partners to improve the local strategic planning and commissioning of short break provision.	Scottish Government Shared Care Scotland
13.3	For the duration of this strategy, the Scottish Government will undertake to strengthen the NHS role as a strategic partner in supporting the provision of respite care. The Scottish Government will facilitate a high level meeting with NHS Boards to consider current practice, with a view to identifying factors which would help promote/support joint working in this area.	Scottish Government NHS Boards Shared Care Scotland
13.4	For the duration of this strategy, the Scottish Government with Shared Care Scotland and other	Scottish Government

	partners will encourage and support the continued development of more effective ways of providing short breaks through learning networks and, where possible, the setting up of demonstration projects.	Shared Care Scotland - with partners
13.5	From 2011, the Scottish Government will work with a range of organisations to explore the potential to develop short breaks provision through volunteers.	Scottish Government - with partners
13.6	For the duration of this strategy, the Scottish Government will work with a range of partners to explore the potential to develop emergency respite and to support carers with emergency planning.	Scottish Government - with partners
13.7	The Scottish Government will continue to publish official statistics on respite provision and will work to improve the quality and consistency of this information, in order to achieve National Statistics status for this data source and publication.	Scottish Government Shared Care Scotland - with partners
13.8	By July 2012, the Scottish Government will reassess the timescale for delivery of the Manifesto commitment to a guaranteed annual entitlement to breaks from caring for those in greatest need, taking account of progress in the delivery of short breaks through the other Action Points in this chapter.	
14.	**TRAINING – CARERS AND WORKFORCE**	
14.1	The National Carers Organisations will use the £281,000 grant from the Scottish Government to allocate grants to a range of organisations for carer and workforce training in a transparent and outcome-focused way. The NCOs will ensure dovetailing with the NHS Board Carer Information Strategies.	NCOs NHS Boards
14.2	NHS Boards will build on the carer training provided under the Carer Information Strategies and continue to train carers beyond 2011. Subject to the outcome of the Spending Review, the Scottish Government will work with NHS Boards so that they will make a training offer to carers.	NHS Boards
14.3	In 2010-12, NHS Education for Scotland (NES), in collaboration with NHS Boards and the national carer organisations, will review existing training, education and learning modules for working with carers and ***young carers;*** identify core competencies for NHS staff in identifying and supporting carers and ***young carers;*** and identify packages and materials to be incorporated within core induction, education and training curricula.	NHS Education for Scotland - with NHS Boards, NCOs, and councils
14.4	NES will communicate to the relevant regulatory, professional and national bodies the importance of identifying and supporting carers and ***young carers*** in workforce training and education.	NES
14.5	From 2010 onwards, the Scottish Government will work with NHS Boards to ensure that identifying	Scottish Government

	and supporting carers and ***young carers*** is embedded in workforce training.	- with NHS Boards
14.6	In 2009-10, the Scottish Government will continue to promote the benefits of workforce training through the Scottish Social Services Council (SSSC), the national carer organisations and others.	Scottish Government
14.7	In 2011-12, NES and the NCOs will produce a good practice guide to workforce training. This will be widely distributed.	NES NCOs
15.	**HOUSING AND HOUSING SUPPORT**	
15.1	For the duration of this strategy, the Scottish Government and COSLA will work with local authorities, housing associations, the independent rented sector, Health Boards and other partners to ensure that the needs and views of carers are taken into account in developing more effective links between housing, social care and health policies and services.	Scottish Government COSLA - with partners
13.2	Carers' views will be taken into account during public engagement events in 2010 on the Reshaping Care for Older People programme. These views will help shape the development of that programme.	Scottish Government
16	**USE OF ASSISTIVE TECHNOLOGY – TELECARE and EQUIPMENT & ADAPTATIONS**	
16.1	In 2010-11 the Scottish Government, with local authority and other partners, will raise awareness of telecare amongst carers nationally and locally and will ensure that carers have better access to appropriate information on services.	Scottish Government - with councils and other partners
16.2	The Scottish Government, with Carers Scotland, will ensure that carers' training is included as part of a national approach to telecare education and training, with a specific workstream developed to address this over 2010-12.	Scottish Government - with Carers Scotland
16.3	In 2010-12, the Scottish Government will ensure that telecare is included in the practical guide to undertaking carers' assessments and will promote its further integration within Single Assessment and Care Management/Review protocols and processes.	Scottish Government
16.4	By 2015, the Scottish Government will have further maximised the impact of its telecare investment to ensure that the benefits and applications of the new technology for carers continues and develops.	Scottish Government
16.5	In 2010-2015 the Scottish Government will further explore the innovative use of new technologies in support of carers living in remote and rural areas, and will identify mechanisms which may be more accessible ***to young carers.***	Scottish Government
16.6	In 2010-15, the Scottish Government, with local authorities, Health Boards and other partners, will raise awareness of equipment and adaptations amongst carers and ensure that carers have better	Scottish Government Councils

	access to appropriate information and training on equipment.	Health Boards
17.	**ADVOCACY SUPPORT**	
17.1	The Scottish Government and COSLA acknowledge the value and benefit of carer advocacy. From 2011 onwards, we will encourage local authorities, NHS Boards and other local partners to develop or expand carer advocacy services for those in greatest need. We will also examine in 2011-12 the scope for producing guidelines on carer advocacy.	Scottish Government - with councils, NHS Boards and other partners.
18.	**EMPLOYMENT AND SKILLS**	
18.1	In 2010 and beyond, the Scottish Government will: - encourage public bodies,[42] through identifying good practice, to promote carer friendly employment practices; - identify ways in which the Scottish Government can work with employers and others to promote carer friendly employment practices. The Scottish Government's Employability Learning Network (ELN) will help with this, including consultation with employability stakeholders.	Scottish Government - with Carers Scotland
18.2	By September 2011, Skills Development Scotland will increase awareness of its services and resources with carers' centres in Scotland, facilitated by the Princess Royal Trust for Carers (PRTC).	Skills Development Scotland - with PRTC
18.3	By December 2011, Skills Development Scotland will explore the opportunities afforded to carers by its partnership with JobCentre Plus, to develop an Integrated Employment and Skills service.	SDS - with JobCentre Plus
18.4	By March 2012, Skills Development Scotland, the national carer organisations and the network of carers centres will work together to begin to: - identify the learning, career aspirations and employability requirements of carers; - identify ways in which SDS services can be more effectively targeted to help carers into training and employment.	SDS - with NCOs and carers centres
19.	**TACKLING POVERTY: FINANCIAL INCLUSION**	
19.1	The Scottish Government will pursue the new UK Government, as it did with the previous administration, the level of the Carer's Allowance and a review of financial support to carers.	Scottish Government
19.2	The Scottish Government will work with local authorities and the NHS to enhance the role of Single	Scottish Government

[42] The bodies funded by the Scottish Government (which excludes the Further and Higher Education sectors and local authorities)

	Shared Assessments and Carers Assessments as opportunities to promote financial inclusion for carers.	-with councils and NHS
19.1	COSLA will create a benchmarking network to facilitate consistent approaches to charging for non-residential social care services across local authorities. Work will be undertaken annually to assess levels of consistency across Scotland. As part of this process COSLA will engage with national carers organisations to listen and respond to any concerns.	COSLA - with councils and NCOs

Appendix 4

Scottish Government investment in carers and young carers since 2007

Recipient	Purpose	Amount
NHS Boards and Scottish Ambulance Service	Carer Information Strategies (CIS) 2008-09 to March 2011	£9 million over three years (£1m/£3m/£5m)
Local authorities	Delivery of 10,000 additional respite weeks by 2011	£4.19 million in 2009-10 and 2010-11 as part of the local government settlement
National carer organisations (NCO) core funding	Sustainability of NCOs	£1.275 million between 2007 and 2011
NCO project funding – to different NCOs	A number of different projects: 1) Carer training pilots (BME, rural, Lothian) 2) Use of direct payments in rural areas 3) Learning for Living 4) Short breaks research 5) Carer and workforce training 6) Miscellaneous (Eurocarers, Engagement Events) 7) Three young carer initiatives (primary-aged young carers/mental health and well-being/transitions) 8) Three young carer festivals 9) Young carer mapping project 10) Young carer project sustainability funding	£1.349 million between 2007 and 2011

Appendix 5

Care 21 Recommendations and Progress since 2006

Recommendation 1
We recommend that the Scottish Executive should develop a Carers Rights Charter in Scotland.

1. The Care 21 Report contained a vision statement articulating a rights-based vision for carers. The rights set out included the right to work, the right to rest and leisure, including reasonable limitation of working hours, the right to training and education, the right to access services and the right to a standard of living adequate for health and well-being.

2. The then Scottish Executive stated in its response that a Carers Rights Charter was not one of its immediate priorities.

3. The Work and Families Act 2006 gives carers in employment the right to request flexible working patterns. The Equality Act 2010 (to be commenced) enshrines further rights in law.

Recommendation 2
We recommend that a national forum representing the views of young carers be established and supported by a separate Young Carers Strategy.

4. See Getting it Right for Young Carers.

Recommendation 3
We recommend that a range of measures to enable greater control and choice (including shifting the balance of 'purchasing power' to carers and users) be fully explored by the Scottish Executive.

5. The Scottish Government intends to introduce a Self-Directed Support (Scotland) Bill. This would extend direct payments to carers.

Recommendation 4
We recommend the development of a national 'expert carer' programme. This should include training for people to develop their own caring skills, knowledge and expertise.

6. The Scottish Government made carer training an important part of its guidance on NHS Carer Information Strategies. Many NHS Boards, with partners, are funding carer training, including training related to specific conditions.

7. The Scottish Government funded the online carer training 'Learning for Living,' which provides an introduction to caring and a means of enabling carers to consider their future plans.

8. The Scottish Government funded the national carer organisations to take forward carer training pilots with BME carers and with carers in rural areas. We also funded a *Caring with Confidence* Lothian Expert Carer Training Pilot.

Recommendation 5
We recommend that all frontline staff with direct responsibilities for supporting the needs of carers in 'first contact' agencies (local authorities, health and voluntary organisations) are properly equipped to advise unpaid carers about their rights, entitlements and available services.

9. Whilst there is no specific recommendation in Care 21 about the identification of carers, it is implicit in recommendation 5. It is also part of recommendation 6 about the implementation of NHS Carer Information Strategies in all localities.

10. There has been considerable progress over the last few years in carer identification and self-identification. This in turn has resulted in newly identified carers accessing support, including that provided through the network of carers' centres in Scotland.

11. NHS Carer Information Strategies are being implemented in all Health Board areas. Minimum requirements and guidance to Health Boards issued in April 2006[43] made clear that NHS Boards must develop proposals to identify carers and demonstrate that NHS staff are aware of the need to identify carers and to signpost them to sources of support. All NHS Boards submitted progress reports for 2008-09, with further reports for 2009-10 due later in 2010. More carers are being provided with information and advice, or are being signposted or referred to relevant sources of advice.

12. The Carer Information Strategies being taken forward by NHS Boards are helping to train health and social care staff in carer and ***young carer*** awareness and carer and ***young carer*** support. Many health and social care staff do recognise carers' and ***young carers'*** needs and are working with carers as partners in care.

[43] NHS Carer Information Strategies: Minimum Requirements and Guidance on Implementation, NHS HDL (2006) 22, 24 April 2006

Recommendation 6
We recommend NHS Carer Information Strategies should be implemented as an early priority in all localities and that the requirements are extended to include local authorities.

13. See recommendation 5.

14. Local authorities are identifying and supporting carers. The Scottish Government has no current plans to formally extend the CIS requirements to local authorities.

Recommendation 7
We recommend that professional training for all health and social care staff should include a substantial component which relates to unpaid carers as partners in care, carers' needs and the diversity of the unpaid caring experience.

15. The NHS Board Carer Information Strategies, national carer organisations and others have taken forward workforce training.

Recommendation 8
We recommend a greater role for carer representative organisations in the joint planning and development of care and other services (especially housing, leisure and transport) at a national and local level.

16. National carer organisations and carers are involved in a wide range of strategic developments at national level, including engagement in Changing Lives, Shifting the Balance of Care, Reshaping Care and the development of telecare services.

17. At local level, NCOs and carers are involved in the planning and development of short breaks' services and other forms of support.

Recommendation 9
We recommend that the Scottish Executive and other policy makers integrate the issues facing unpaid carers into their policy development and planning processes.

18. At Scottish Government level, this has been taken forward through various policy developments, including those in relation to health inequalities, mental health, dementia, learning disabilities, independent living,Reshaping Care and Shifting the Balance of Care.

Recommendation 10
We recommend that service providers ensure they meet the needs of the whole caring community, taking account of carers with special needs and the specific cultural and language needs of minority ethnic groups.

19. This recommendation is primarily for service providers. However, this strategy encourages service providers to meet the needs of all carers, especially carers in greatest need and those carers who are in the hard-to-reach groups.

Recommendation 11
We recommend that the Scottish Executive continues to update the Carers Strategy to incorporate the impact of demographic and social change and to plan for resourcing of future need.

20. See recommendation 22. Also, this strategy sets out the full implications of demographic and social change in relation to support for carers.

Recommendation 12
We recommend that carers' organisations should have a greater role in the inspection of local services that support unpaid carers and users.

21. Carers are represented on the Care Commission Board, and are appointed as lay members to the Scottish Social Services Council Registration and Conduct Committees. All of SWIA's performance inspections of councils involve carers as inspectors. SWIA, in partnership with Carers Scotland, recruited a bank of 18 carers employed as inspectors and run training for carer inspectors with Glasgow College for Nautical Studies.

Recommendation 13
We recommend that local authorities should work with unpaid carers to develop person-centred life plans alongside the established carers' assessment process.

22. The Government's framework of outcomes for carers and service users, *Talking Points*, focuses on the outcomes that carers wish to achieve from the assessment process. The National Minimum Information Standards (NMIS) reiterate this position.

23. Carer's Assessment Guidance for National Standards is available as an Annex to NMIS. The emphasis is on improving outcomes for carers.

24. The guidance is also clear that assessments must be 'culturally competent' in relation to BME carers. The idea of 'cultural competence' has wider applicability to other groups of carers.

25. The Scottish Government is working with partners so that they better understand the importance of the carer's assessment (carer support plan). The aim is to increase uptake and to advance this as a means of ensuring better outcomes for unpaid carers in Scotland.

Recommendation 14
We recommend that the UK Government complete an early review on carers' benefit entitlements, tax credit and pensions with a particular focus on removing the barriers to work which are inherent in the way current financial arrangements are constructed.

26. The earnings threshold for receipt of the Carer's Allowance increased from £95 a week to £100 a week from April 2010. This is the responsibility of the UK Government.

27. The Pensions Act 2008 introduced a new Carer's Credit (from April 2010) which awards carers with National Insurance contributions in order to protect their state pension even if they are not in paid work.

28. The Scottish Government included families with a child under 16 as a group which qualifies for enhanced measures under the Scottish Energy Assistance Package. This helps parent carers of disabled children.

Recommendation 15
We recommend that the UK Government should develop a national awareness campaign to ensure that employers of all sizes are made more aware of both their roles and their responsibilities towards carers, and the overall contribution of unpaid carers.

29. The Action for Carers and Employment initiative[44] has raised awareness of the personal and economic implications of carers leaving the paid workforce and is lobbying for change.

30. The Work and Families Act 2006 provides carers with the right to request flexible working patterns if certain conditions are met. Employers are expected to comply and to agree to the requests for flexible working unless there are good reasons for not doing so.

31. JobCentre Plus introduced Work Focused Support for Carers (WFSC) in December 2009 as part of a carer-specific programme to improve the help and advice available to carers who wish to re-enter the job market. The service is entirely voluntary and carers are free to leave at any time. Care Partnership Managers are in place in all JobCentre districts in Scotland (and the rest of the UK) and advisers are in place in local Jobcentres.

[44] Action for Carers and Employment 2003-2008, Carers UK and Carers Scotland with partners

32. Carers UK, supported by partners and Carers Scotland, have promoted good practice on flexible working and have highlighted to employers the skills which carers bring to the workforce.

33. City and Guilds, in partnership with Carers Scotland, has developed a personal development and learning tool for carers, *Learning for Living,*[45] consisting of online learning resources for carers and a qualification. This qualification is designed to help carers to remain in, or return to, paid employment or to progress on to further learning.

Recommendation 16
We recommend that the Scottish Executive, local authorities and NHS agencies along with partner agencies, focus strongly on the health and wellbeing of unpaid carers.

34. The overarching aim of the **Carer Information Strategies** is to enable carers to continue in their caring role, whilst protecting their own health and well-being.

35. The Scottish Enhanced Services Scheme for carers is in place in eight Area Health Boards. GP practices in these areas, often with *in situ* workers from the Third Sector, are supporting carers, and sometimes ***young carers,*** in a number of different ways. These include providing information and advice on carers' health and well-being, signposting on carers to sources of support and providing advice on benefits. Some practices have set up carers' registers to ensure they are aware of their carer population and also to identify people as carers.

36. The Scottish Government continues to fund ***Breathing Space,*** the free, confidential, out-of-hours telephone advice and signposting service for people experiencing low mood, depression or anxiety. It is available to all, including carers. It is run by NHS24 and the number is **0800 83 85 87.**

37. In August 2008 NHS24 launched ***Living Life,*** a pilot telephone cognitive behavioural therapy service for people who are feeling low, depressed or anxious. It is available by referral from selected GP surgeries and, by self-referral, in five health board areas. It is part of the Scottish Government's commitment to increase the availability of evidence-based psychological therapies in a range of settings and through a range of providers. In 2009 an additional pilot project was launched to support the commitment to increase availability of evidence-based psychological therapies – the 'WISH' pilot is hosted by NHS Greater Glasgow and Clyde, and involves 3 other Boards.

38. The Scottish Government, working with a range of partners, has developed a national mental health improvement campaign called ***Steps for Stress***. This forms part of the Government's mental health improvement

[45] Learning for Living
www.carersscotland.org/Policyandpractice/Traininganddevelopmentforcarers/LearningforLivin
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policy and action plan ***Towards a Mentally Flourishing Scotland***. The printed booklet is available in community settings such as GP surgeries, libraries, pharmacies and Citizens Advice Bureaus.

39. The ***Life Begins at 40*** pilot, which started in May 2010, is also relevant. It is now available to all people, including carers approaching the age of 40 in Grampian. It aims to:

- provide access to a set of health related questions for all people reaching the age of 40 in order to assess their current state of health and, on the basis of their answers, to provide them with health information and/or any key areas for action which might help improve their current and future health;
- be available through an interactive online questionnaire or by calling the NHS Helpline number where an NHS 24 Health Information Advisor will take the caller through the questionnaire;
- be available to and for that part of the entire Scottish population who are either approaching or at their 40th birthday.

40. In response to the Children's Commissioner's report ***'Handle with Care,'*** Ministers approved in 2009 a number of proposed actions addressing issues surrounding the manual moving and handling of children and young people with disabilities.

Recommendation 17
We recommend that issues facing unpaid carers are given proper consideration when new technology is applied to caring situations.

41. Over 25,000 people in Scotland have received a telecare service as a result of the National Telecare Development Programme. The Scottish Government launched this programme in 2006 with substantial investment of over £20 million to help local authorities accelerate the adoption of supportive technologies within mainstream care provision.

42. New guidance on the provision of equipment and adaptations was issued by the Scottish Government in December 2009[46]. The guidance aims to assist local authorities and their NHS partners to modernise and integrate their equipment and adaptations services within the wider community care context.

Recommendation 18
We recommend that Scotland's existing network of local carer support organisations is strengthened (carer training and peer support; emotional support and counselling; breaks from caring; advocacy).

43. The Scottish Government provides core and project funding to the national carer organisations. Some local authorities and Health Boards fund local carer centres. The Lottery programmes have also funded centres.

[46] CCD 5/2009: Guidance on the Provision of Equipment and Adaptations

44. See responses under recommendations on carer training, health and well-being and breaks from caring.

Advocacy

45. Since 2000, the Scottish Government and Scottish Independent Advocacy Alliance (SIAA) have led the development of independent advocacy in Scotland.

46. The Scottish Government is committed to ensuring that there is appropriate provision across Scotland of advocacy for people who need it. One of the achievements has been the inclusion of a right of access to independent advocacy in the *Mental Health (Care and Treatment) (Scotland) Act 2003.* The Independent Living Shared Vision looks towards disabled people having access to a range of structured, valued and accessible advocacy services to support their access to independent living in all aspects of day to day life.

47. Earlier this year, SIAA produced A Guide to Commissioners and Principles and Standards[47] and an Evaluation Framework Toolkit[48] Some additional work is planned around the development of guidance on advocacy for children and young people. In 2008 the SIAA published updated Principles and Standards for Independent Advocacy[49] and an associated Code of Practice for Independent Advocacy.[50] The SIAA has also developed a leaflet which gives advice on Advocacy for Families and Carers.[51]

48. The SIAA is currently reviewing and updating the Map of Advocacy provision across Scotland. When completed this should help identify gaps in provision of advocacy services.

49. The Patient Rights (Scotland) Bill aims to place patients at the centre of the NHS in Scotland. This healthcare legislation, if approved by the Scottish Parliament, will help ensure that patients' rights and entitlements are more widely understood and used.

50. One of the key aspects of the Bill is the creation of a new Patient Advice and Support Service (PASS) within Health Board areas. This will be staffed by Patient Rights Officers who will help and support patients and members of the public to make complaints, will provide information about health services, and will direct them to other useful types of support, including advocacy.

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[47] http://www.siaa.org.uk/documents/guide-for-commissioners/siaa_guide_for_commissioners.pdf

[48] (http://www.siaa.org.uk/documents/evaluation-framework/Evaluation_framework_complete.pdf).

[49] http://www.siaa.org.uk/images/stories/siaaprinciples%26standardsforweb.pdf

[50] http://www.siaa.org.uk/images/stories/siaacodeofpracticeforweb.pdf

[51] (http://siaa.org.uk/images/leaflets/guide-to-advocacy-for-families-and-carers.pdf)

51. The Scottish Government is providing funding of £1.5 million to assess need and provide additional advocacy services over three years in order to improve access.

52. The Independent Advice and Support Service (IASS) funded by NHS Boards is available in all NHS Board areas to provide support for people who have concerns or wish to make a complaint about NHS services. It is proposed under the Patient Rights (Scotland) Bill to enhance and replace IASS with a new Patient Advice and Support Service.

Recommendation 19
We recommend that national carer organisations focus on their collective role as the 'voice of carers' and coordinate effectively their capacity in the planning, development and monitoring of carer policy and support services.

53. This is a matter primarily for the national carer organisations, who work together on various initiatives. The Scottish Government encourages such joint working and will be encouraging this further in the years ahead.

Recommendation 20
We recommend that as an urgent priority the Scottish Executive develops a national strategic framework with service providers to ensure unpaid carers are given a statutory entitlement to appropriate short breaks and breaks from caring.

54. There is no statutory entitlement to short breaks.

55. The Scottish Government, with COSLA and partners, issued guidance in December 2008 on short breaks (respite). http://www.scotland.gov.uk/Publications/2008/11/20094716/0. Scottish Government Ministers have publicised this guidance, which sets out key issues about short breaks including the purpose of short breaks, choice and personalisation and strategic planning. It contains good practice examples.

56. Under its Concordat agreement with local government, the Scottish Government has committed funding of £4.19 million in 2009-10 and 2010-11 so that local authorities can deliver an additional 10,000 respite weeks by 2011 in comparison with 2007-08.

57. In 2008-09, local authorities increased respite weeks across Scotland by 1,150 weeks. The 2009-10 figures are due in the Autumn.

58. The Scottish Government is proactively working with Shared Care Scotland and other organisations to consider and take forward innovative solutions around short breaks provision.

59. The findings of the research, funded by the Scottish Government and commissioned by Shared Care Scotland, which will be available later in the

summer, will be widely disseminated. The Scottish Government and Shared Care Scotland expects this research to help inform decisions at national and local level about short breaks' provision.

Recommendation 21
We recommend that the report's recommendations are incorporated into providers' performance management systems and progress monitored by the Scottish Executive and, where appropriate, relevant regulatory and inspection bodies.

60. Many statutory and voluntary sector providers will be aware of Care 21's recommendations. SWIA takes account of the recommendations in its inspection of services for service users and takes carers' views into account. The provision of respite weeks (10,000 weeks by 2011) is monitored under the Concordat agreement. The Scottish Government's response to this recommendation will be further developed through this strategy. Local authorities, do, however, have responsibility for determining priorities at local level.

Recommendation 22
We recommend that good policy must continue to be based on good research including reliable statistical evidence with attention to the diverse experiences of unpaid carers.

61. The Scottish Government is publishing at the same time as this strategy a research publication, ***'Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland.'*** For the first time this brings together in one place all the statistical data on carers.

62. The main sources of information on the prevalence, intensity and trends in caring up until now have been the 2001 Census and the Scottish Household Survey. The Scottish Household Survey questions have been refined over the years to get better information on carers.

63. The 2011 Census will contain a question on caring similar to that in the 2001 Census. There will be a further breakdown on hours of caring: the 20-49 hours per week category will be split 20-34 hours and 35-49 hours per week, to bring the Census in line with the Scottish Household Survey and also to determine the number of carers providing 35 or more hours per week, the current threshold for Carer's Allowance.

64. The Scottish Health Survey provides a detailed picture of the health of the Scottish population. In 2008, the Scottish Health Survey began to collect information on carers for the first time and some results are published in the research publication noted above.

65. The Scottish Government is now publishing, as Official Statistics, information on respite services provided by each council in Scotland. This data will be used to monitor the Concordat Commitment to increase respite services by 10,000 weeks by 2011. The latest publication is available at:

http://www.scotland.gov.uk/Publications/2010/02/22113516/0 The Scottish Government is working with local authorities to improve the quality and consistency of this information.

66. As part of its performance inspection of social work services between 2005 and 2009 the Social Work Inspection Agency (SWIA) carried out a survey of carers who are in contact with social work services. There were 3,599 questionnaires returned across Scotland. The results of the survey can be found on the SWIA website at: http://www.swia.gov.uk/swia/findstatsdocument.htm?message=blank

Appendix 6

Number of Unpaid Carers by Local Authority Area

Local Authority	Number of Unpaid Carers
Aberdeen City	25,111
Aberdeenshire	29,036
Angus	12,133
Argyll and Bute	10,790
Clackmannanshire	8,690
Dumfries and Galloway	22,216
Dundee City	14,027
East Ayrshire	21,844
East Dunbartonshire	12,862
East Lothian	13,095
East Renfrewshire	9,772
Edinburgh City	47,404
Eilean Siar	2,933
Falkirk	21,929
Fife	49,522
Glasgow City	66,371
Highland	29,523
Inverclyde	9,892
Midlothian	14,192
Moray	11,628
North Ayrshire	18,921
North Lanarkshire	48,957
Orkney Islands	1,989
Perth and Kinross	19,082
Renfrewshire	24,087
Scottish Borders	12,502
Shetland Islands	2,246
South Ayrshire	15,283
South Lanarkshire	38,023
Stirling	12,050
West Dunbartonshire	13,132
West Lothian	18,086
All Scotland	657,328

Source: Scottish Household Survey, 2007-08

Appendix 7

Remote and Rural Areas - Transport

The National Transport Strategy (NTS)

In December 2006, the Scottish Government published a National Transport Strategy (NTS) which sets a 20 year vision for transport in Scotland. To ensure we are continuing to reflect the Government's priorities for transport, we are currently refreshing the NTS.

The Scottish Government is committed to sustaining the viability of remote and fragile communities through ensuring access to lifeline air and ferry services.

We are also committed to maintaining and improving access for rural Scotland. This involves ensuring a high quality public transport system as well as supporting the development of community transport solutions.

Smarter Choices, Smarter Places

The Smarter Choices, Smarter Places programme is a £15m three-year programme in seven local project areas, supported by Scottish Government and COSLA. It has two rural projects, Dumfries and Kirkwall. They are doing some very interesting and worthwhile work on encouraging local sustainable transport solutions.

Scottish Ferries Review

The Scottish Ferries Review will inform the Scottish Government's long term strategy for lifeline ferry services in Scotland to 2022. The review includes a detailed appraisal of routes to determine whether a better configuration could be developed to better serve our island communities while contributing to our overall purpose of increasing sustainable economic growth. A further round of consultation events on the Draft Consultation Document will take place in the summer of 2010.

Road Equivalent Tariff (RET)

The Scottish Government is committed to ensuring that all remote and fragile communities have direct links to the greater Scottish economy. We understand the genuine concerns from Scotland's remote and fragile communities about the affordability of ferry travel and the impact that has on island communities. That is why we have launched a pilot exercise which seeks to establish the benefits of a road equivalent tariff (RET) as a basis for future ferry fares. The pilot which runs on all Western Isles to mainland routes began in October 2008 and will run until spring of 2011. An interim evaluation of the RET pilot will feed into the Scottish Ferries Review.

Lifeline Air Services

The Scottish Government subsidises 3 Public Service Obligation (PSO) routes from Glasgow International Airport to Campbeltown, Tiree and Barra under European rules. In addition, there are a number of PSOs imposed by local authorities. These lifeline PSO routes recognise the importance of air services which would not otherwise be commercially viable but are essential for social cohesion and sustainability of Scotland's remotest communities.

Air Discount Scheme

The Air Discount Scheme is designed to facilitate a better level of social inclusion for those resident in some of the most peripheral parts of Scotland. Residents benefit from a 40% reduction on the core fare for air travel. The Scheme has proved popular with residents since it was introduced. As well as reducing the cost of air travel, it improves connectivity and reduces journey times in the Highlands and Islands.

Rural Transport Fund

From April 2008, the funding for the Rural Public Transport Grant Scheme and the Rural Community Transport Initiative, two elements of the Rural Transport Fund, was absorbed into the block local government settlement. It is now for local authorities to determine their priorities and to allocate funding accordingly for community transport services in more remote areas of Scotland where there are no scheduled or limited public transport services.

Rural Petrol Stations Grant Scheme

The third element of the Rural Transport Fund is the Rural Petrol Stations Grant Scheme, which recognised the importance of car use in remoter areas and supported rural filling stations. From April 2008 it became the responsibility of Highlands and Islands Enterprise and Scottish Enterprise. HIE Area Offices are able to provide financial assistance to filling stations located in HIE's Fragile Areas, as part of their 'Growth at the Edge' initiative.

Rural Fuel Prices

The Scottish Government has concerns about the relatively high price of fuel in remote rural and island communities and the disproportionate burden that this places on households and businesses in these areas. Fuel duty is a reserved area. However, we have written a number of times to suggest to the UK Government that Scotland could press the European Union for a derogation to apply a lower rate of fuel duty in rural areas, recognising the accessibility and price disadvantages faced by Scotland's remote and island communities.

Strategic Transport Projects Review

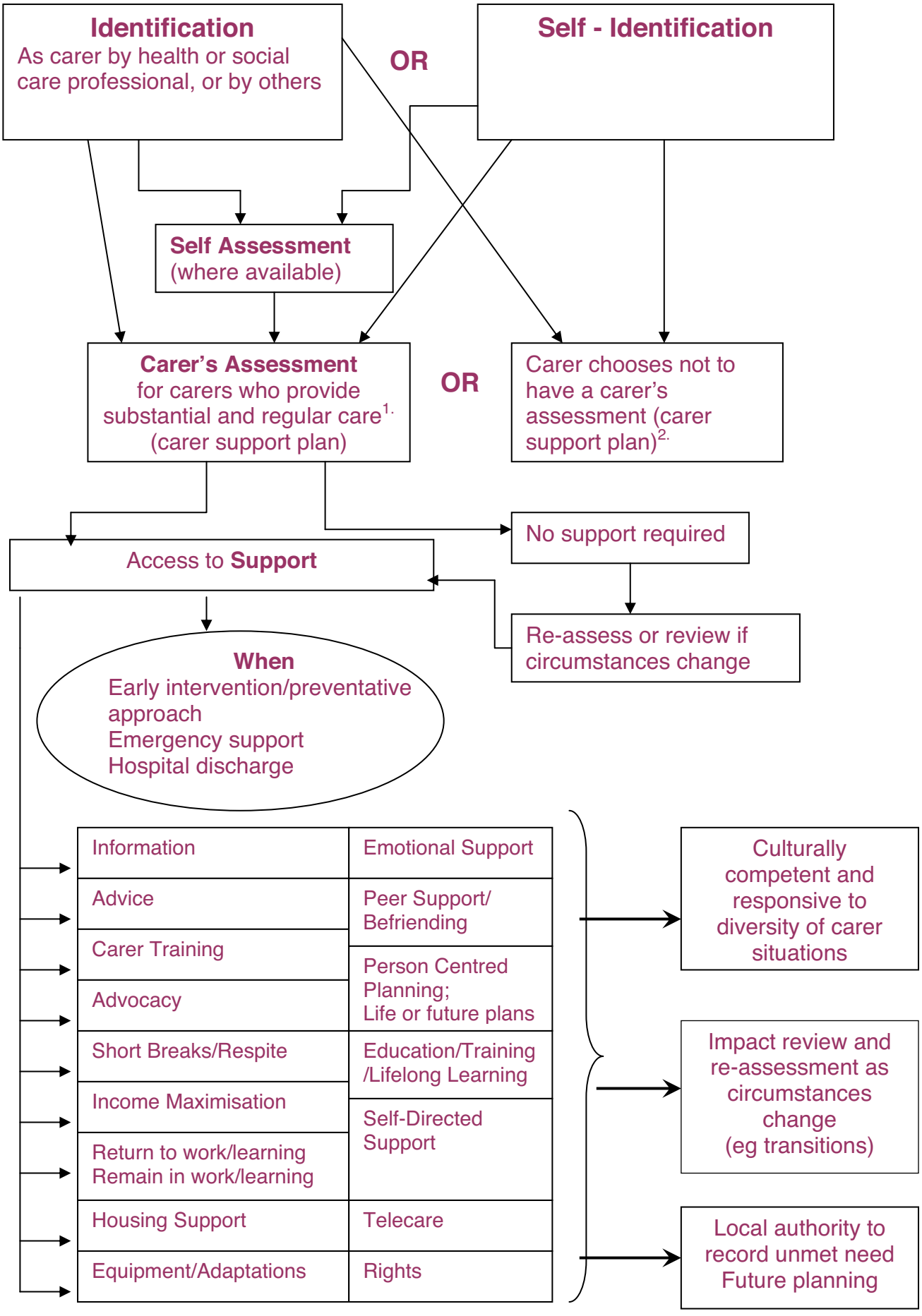
The Strategic Transport Projects Review (STPR) is a multi-modal approach to achieving a balanced and sustainable strategic transport network which provides better connections across Scotland. The Review recommends a number of improvements to Scotland's rail network, including rural lines in the Highlands, such as the construction of new rail stations at Dalcross and possibly Kintore. However, the STPR does not preclude Regional Transport Partnerships and local authorities from considering the value of regional and local transport interventions.

Public Transport - Bus

The Scottish Government is committed to supporting our bus industry. The recently announced three year agreement with the Confederation of Passenger Transport on the Bus Service Operators Grant and Concessionary fare reimbursement will deliver another £740m of significant investment. This will help deliver benefits to Scottish bus passengers, enabling them to travel on a large bus network for a reasonable fare. Concessionary passengers can continue to enjoy free travel all over Scotland including residents of the Western Isles, Orkney and Shetland who are entitled to two free return ferry journeys to the mainland each year. Funding through the Concordat provides local government with the authority to invest in local priorities, such as demand responsive transport and the development of new sustainable bus routes, and to support bus services where required. Latest statistics indicate that public transport support of local bus services by local government was £53 million in 2008-9.

Carer Pathway

Appendix 8



[1.] Under the Social Work (Scotland) Act 1968, as amended by the Community Care and Health (Scotland) Act 2002, carers who provide a "substantial amount of care on a regular basis" are entitled to an assessment.

[2.] Carers who provide substantial and regular care who choose not to have a carer's assessment can nonetheless access support. However the preferred route to support is via a good quality carer's assessment.

Appendix 9

Fuel Poverty - Energy Assistance Package

1. The Energy Assistance Package (EAP), launched on 6 April 2009, aims to tackle fuel poverty by providing a four-stage package of help targeted at those most in need:

- Stage 1 energy advice is available to all who contact the managing agent for the scheme.
- Stage 2 provides help with improving incomes through benefit checks and, reducing energy bills by moving applicants, where appropriate, on to their energy providers social tariff.
- Stage 3 provides a eligible households with loft and cavity insulation, where this is needed.
- Stage 4 can provide enhanced energy efficiency measures such as central heating, air source heat pumps, external and internal wall insulation.

2. A household is eligible for assistance if the house has an energy rating of bands E, F and G and they are in receipt of a qualifying benefit. Help is also available for people over 60 who live in a house that doesn't have a central heating system and for those over 75 who live in an energy inefficient dwelling.

3. The package is available to property owners and private sector tenants. Social landlords have a programme to improve their properties to meet the Scottish Housing Quality Standard and so are not eligible.

4. EAP is tackling rural fuel poverty by including a wide range of measures such as external and internal wall insulation and air source heat pumps for hard-to-treat homes.

5. Advice on income maximisation is available to everyone who calls the freephone number.

6. From 10 May 2010 new Regulations came into force extending the eligibility criteria to include all children under the age of 16 where families receive a qualifying benefit and live in an energy inefficient home. Prior to this, the eligibility criteria included families with disabled children under the age of 16. The Scottish Government monitors the uptake of the energy assistance package.

7. Information on the Energy Assistance Package is available by calling the freephone number 0800 512 012 or by accessing www.energyassistancepackage.com.

Appendix 10

Glossary of Terms and Definitions

Alcohol and Drug Partnerships (ADPs)	Alcohol and Drug Partnerships (ADPs) have been set up for every local council area to transform the provision of services to tackle substance misuse. ADPs are developing and implementing local alcohol and drugs strategies to reduce the numbers of people with substance misuse problems.
Association of Directors of Social Work (ADSW)	ADSW is the professional association representing senior social work managers in local government in Scotland.
Black and Minority Ethnic (BME)	Any minority group who has a shared race, nationality, language and culture. House of Lords definition of an ethnic group – "Essential features are a long shared history and a common cultural tradition. There may also be some of the following present: common geographical location from a small number of ancestors; a common language; a common literature; a common religion; and, being a minority within a larger community." An alternative definition is: "A group of people who share certain background characteristics such as common ancestors, geographical origin, language, culture and religion. This provides them with a distinct identity as seen by both themselves and others."
Community Health Partnerships (CHPs)	Community Health Partnerships were established by NHS Boards as key building blocks in the modernisation of the NHS and joint services, with a vital role in partnership, integration and service redesign.
Concordat	The agreement in November 2007 between the Scottish Government and local government, based on mutual respect and partnership. It underpins the funding to be provided to local government to March 2011.
Convention of Scottish Local Authorities (COSLA)	The representative voice of Scottish local government and the employers' association on behalf of all Scottish councils.
Direct payments	Payments from councils in lieu of services provided directly to individuals assessed as being in need of community care services. The amount of money received depends on the assessed needs. The legal provisions relating to direct payments are contained within a number of Acts and Regulations. The main duties are set out in Section 12B and 12C of the Social Work (Scotland) Act 1968 and the accompanying Regulations from 2003. However, these have been updated over a number of years.

Independent Living	Promotes independent living for disabled people with choice, control and quality at the heart of the provision.
Keep Well and Well North	Keep Well and Well North programmes provide health checks in some of the most deprived areas of Scotland. They were set up to reduce health inequalities by identifying people aged between 45 and 64 in deprived communities who are at risk of cardiovascular disease and offering interventions to reduce their risk. The upper limit of 64 reflects the objective of preventing premature mortality and morbidity, premature being defined as before age 75.
Lesbian, Gay, Bisexual and Transgender (LGBT)	Lesbian, gay, bisexual and transgender people.
National Carer Organisations (NCOs)	The 5 voluntary organisations representing carers issues on a national basis: - Carers Scotland - Coalition of Carers in Scotland (COCIS) - Crossroads Caring Scotland - Princess Royal Trust for Carers - Shared Care Scotland
NHS *inform*	A single gateway provided by NHS 24 for the provision of quality assured health information for the population of Scotland.
Personalisation	Personalisation fundamentally moves the location of power, decision-making and expertise from the system to the people who may need support. It is the practical application of principles and values that aim to support, encourage and assist individuals to retain, reclaim or discover elements of themselves that are essential to their humanity. In this new environment, more people will not require formal services. A 'one size fits all' approach is not what we want for ourselves, but can be what we deliver. (ADSW – Personalisation 2009)
Public Partnership Forums (PPFs)	Public Partnership Forums (PPFs) are the main structure by which the Community Health Partnerships (CHPs) link with the people of the communities that they serve, so that there is a meaningful and continuing dialogue with local people.
Reshaping Care for Older People	The reshaping care for older people programme is being developed as current service configuration for care for older people is not sustainable given the demographic and financial pressure we face over the next 20 years. The Scottish Government, NHS and COSLA have embarked on a major programme to engage all interests in reshaping care and support services so that we meet policy objectives in ways

	that are sustainable. There is a need to look carefully at how well current services help older people to optimise their independence and well-being and to make the necessary changes.
Scottish Drugs Recovery Consortium (SDRC)	The newly established consortium was launched on 1 June 2010. The SDRC is an independent national membership organisation established to drive and promote recovery for individuals, family members and communities affected by drugs across Scotland. The consortium is funded by the Scottish Government to support the implementation and delivery of the 'Road to Recovery' national drugs strategy. SDRC is a company limited by guarantee and is registered as a Scottish charity. The SDRC will be an open and accessible vehicle for all of the key stakeholders – individuals who want to share their experience of recovery, mutual aid and community groups; treatment providers in statutory and non statutory settings; housing agencies; employment and training organisations; primary health providers; and specialist agencies. They will work together with people in recovery and their families to develop pathways to meaningful and sustained recovery. For more information about SDRC visit www.sdrconsortium.org.
Scottish Social Services Council (SSSC)	The Scottish Social Services Council (SSSC) was established in October 2001 by the Regulation of Care (Scotland) Act. The SSSC is responsible for registering people who work in the social services and regulating their education and training.
Self-directed support	The definition of self-directed support is wider than the definition of direct payments. It refers to the method by which individuals and families can have informed choice about the way that support is provided to them. Individual budgets are an allocation of funding given to users after an assessment for support.
Shifting the Balance of Care	Shifting the Balance of Care describes changes at different levels across health and social care, all of which are intended to bring about improvements in health and well-being and better service outcomes. This is to be achieved by providing care which is earlier in the course of a disease, a quicker diagnosis and a treatment process tailored more closely to each person's needs and is delivered closer to home.
Social Work Inspection Agency (SWIA)	The Social Work Inspection Agency (SWIA) is an independent Government agency formed to improve the quality of social work services across Scotland.

	In 2011, there will be a single body for healthcare services and another body for social work and social care services, including child protection and the integration of children's services. The new bodies will take on work in these areas currently done by: Her Majesty's Inspectorate of Education (HMIE); NHS Quality Improvement Scotland (NHS QIS); Social Work Inspection Agency (SWIA); and the Care Commission.
Third Sector	The Third Sector comprises social enterprises, voluntary organisations, co-operatives and mutuals. It has an important role in helping the Scottish Government achieve its purpose of creating a more successful country with opportunities for all to flourish, through achieving sustainable economic growth.