Carers Legislation – Consultation on Proposals – January 2014



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Foreword

Scotland, like every other country, has a carer population. According to the 2011 Census, over 9 per cent of people in Scotland identify themselves as carers providing unpaid care to family or friends. However, there will be a higher percentage of our population who are carers as some people do not identify themselves as carers or are not identified by others.

There are now more people than ever before who are caring intensively, for more hours each week. This means that they are facing considerable challenges. The radical demographic changes we are experiencing will impact on carers, including those who live in the most remote parts of our country.

Young carers too are caring day in and day out for their parents, grandparents and siblings. They are proud to be young carers. They are responsible. They give a lot to society. But their caring responsibilities should not impact adversely on their wellbeing. They need to enjoy their childhood and teenage years and have fun, as they do at the annual Young Carers Festival which we are pleased to fund.

We have put significant effort into supporting carers and young carers over the past few years. Carers and young carers are being supported. But the success of this cannot take away from the fact that many carers are experiencing considerable stress and anxiety and are not being supported. As we heard at the 2013 Carers Parliament, often the carer's wellbeing is affected by the situation of the person or people they care for including lack of seamless, responsive joined-up services. The provisions in both the Public Bodies (Joint Working) Scotland Bill and the Children and Young People (Scotland) Bill will help to address these concerns.

The First Minister was pleased to announce at the Carers Parliament that there is a role for carers" legislation as part of a reform agenda to further support Scotland"s carers and young carers. The First Minister made clear that we would strengthen and extend the rights of carers and young carers.

Our approach is to focus on how we can support carers and young carers efficiently and effectively, on a preventative basis, but also to be able to move flexibly to respond properly to crises situations.

This consultation sets out our proposals to improve outcomes for carers and young carers. It also seeks views on some options. I am pleased that we have this opportunity to consult with a wide range of stakeholders, especially carers and young carers themselves, about future developments. In taking forward these proposals I also look forward to the input and comment from other key interests, including local authorities, Health Boards and the Third Sector who are achieving a lot in difficult circumstances. We need the collective insights, knowledge and wisdom to ensure that our proposals for legislation are the best they can be.

Michael Matheson MSP Minister for Public Health

Introduction

What is the purpose of this consultation?

Ministers are clear that we need to accelerate the pace of change so that both adult carers and young carers are fully supported and achieve better outcomes as a result. There is a crucial role for new carers" legislation in raising the bar and providing further impetus to this important agenda.

This consultation paper provides an opportunity for you to offer your views on new legislation that will be introduced to enable the changes that Ministers propose.

Within this consultation we have sought to describe the proposed new legislation in enough context to help inform your answers to the questions we have asked. Nevertheless, this consultation does not – indeed, could not – provide a comprehensive description of every aspect of policy development and practical implementation that will underpin change. Moreover, the fact that both the Public Bodies (Joint Working) (Scotland) Bill and the Children and Young People (Scotland) Bill - which are very relevant to supporting carers and young carers – are before the Scottish Parliament provides further context.

Should the legislation proposed in this consultation pass through the Scottish Parliament the Scottish Government will, with input from a wide range of stakeholders, develop statutory guidance to support the changes that will be enabled by the new legislation set out here. The guidance will provide further important detail to the provisions in the new carers" legislation.

Who should respond to this consultation?

Most of us will either have been a carer at some time in the past, are now a carer or will be a carer in the future. Some of us have been young carers or some young people are now young carers. Some people speak about looking after others without realising that they are describing a caring situation. A wide range of professionals across health, social care, education, housing, sport and leisure and beyond will support carers and young carers. We therefore expect that this consultation will be of interest to a wide range of people, including carers, young carers, cared-for people, and professionals, Directors and Chief Executives across the sectors.

Equality Impact Assessment

The public sector equalities duties require the Scottish Government to pay "due regard" to the need to:

- eliminate discrimination, victimisation, harassment or other unlawful conduct that is prohibited under the Equality Act 2010;
- advance equality of opportunity between people who share a protected characteristic and those who do not; and
- foster good relations between people who share a relevant protected characteristic.

These three requirements apply across the "protected characteristics" of age; disability; gender reassignment; pregnancy and maternity; race; religion and belief; and sexual orientation.

In effect, this means that equality considerations are integrated into all functions and policies of Scottish Government Directorates and Agencies.

A key part of these duties is to assess the impact of all of our policies to ensure that we do not inadvertently create a negative impact for equality groups, and also to ensure that we actively seek the opportunity to promote equality of opportunity and to foster good relations.

We have developed a partial Equalities Impact Assessment (EQIA), attached at **Annex E.** We welcome your feedback regarding the equalities impact of the proposals presented in this paper, and the effect it may have on different sectors of the population.

Business Regulatory Impact Assessment

The Scottish Government is committed to consulting with all parties potentially affected by proposals for new legislation, or where any regulation is being changed significantly.

All policy changes, whether European or domestic, which may have an impact upon business or the Third Sector should be accompanied by a Business Regulatory Impact Assessment (BRIA).

The BRIA helps policy makers to use available evidence to find proposals that best achieve the policy objectives, whilst minimising costs and burdens. Through consultation and engagement with business, the costs and benefits of the proposed legislation can be analysed. It also ensures that any impact on business, particularly small enterprises, is fully considered before regulations are made.

A partial BRIA is attached at **Annex F**. We welcome your views regarding the impact that the proposals presented in this paper may have on businesses, and your comments and feedback on the partial BRIA.

Responses to this consultation

We look forward to receiving your response to this consultation. Please send it to:

CarersandYoungCarersPolicy@scotland.gsi.gov.uk

Or to:

Carers Branch (Consultation) Adult Care and Support Division Directorate for Chief Nursing Officer, Patients, Public and Health Professions Director-General Health and Social Care The Scottish Government 2ER, St Andrew's House Edinburgh EH1 3DG

By: 16 April 2014

Chapter 1

The Case for Change

Introduction

- 1) We are proud of the progress we have made in supporting Scotland's carers and young carers. (Annex A sets out the definition of carer and young carer for the purposes of the proposed legislation).
- 2) In partnership with a wide range of statutory and voluntary organisations and with carers and young carers themselves, much has been achieved in order to improve outcomes for carers and young carers.
- 3) The Scottish Government has made a significant investment amounting to over £112 million between 2007 and 2015 in supporting carers and young carers. This includes: at least £46 million funding between 2012 and 2015 to support carers of older people through the Reshaping Care for Older People Change Fund; over £13 million between 2010 and 2015 for the voluntary sector short breaks fund which is benefitting over 25,000 carers, young carers and cared-for persons; and £29 million to Health Boards for direct support to carers between 2008-2015 which is contributing, amongst other things, to the funding of carers centres and young carers projects across Scotland which provide a wide range of support services including information and advice, advocacy and short breaks.
- 4) Despite the progress that has been made, there is widespread recognition across Scotland that we need to go further. It is clear from research,¹ and from other sources including Change Fund and Carer Information Strategy Plans, that more can be done to improve support to Scotland[®]s carers and young carers.
- 5) The challenges we are facing in terms of the demographic change² impact specifically on carers. It is good that people are living for longer in better health and that older people are significant contributors to Scottish society. Equally, however, the growth in the frail older population with people having dementia and multiple complex conditions is impacting on carers, many of whom are older themselves. There is a pattern emerging now in households of two older people caring for each other in mutually dependent caring situations. People with learning disabilities are outliving their parents and children with complex needs are surviving for much longer.

¹ A body of research over the last few years commissioned by academia, research consultants and the national carers organisations.

² The Registrar General has projected that the number of people in Scotland aged over 75 will grow by around 10,000 every year, over the decade ahead. Changes in demography will vary in scale depending on location. Around one quarter of Scotland's population will be aged 65 and over by 2033. For some of our more rural areas the proportion is predicted to rise to nearly one third.

- 6) The Census 2011 shows little change since the Census 2001 in the percentage of people (9%) who say that they are carers. However, the figures demonstrate a considerable shift towards high intensity caring based on the number of hours each week that people provide unpaid care. There is an increase in the number of hours of care which unpaid carers carry out each week, with 45% (219,000) of them providing 20 or more hours of care a week, compared with 37% (176,000) in 2001. This is 43,000 more carers caring for over 20 hours each week in 2011 compared with 2001. Annex B sets out the breakdown by hours of caring for every local authority area. If we take hours of caring as a proxy for intensive caring which can have a negative impact on carers who are not adequately supported, then there are more carers requiring more support.
- 7) Caring can impact on carers in many ways and in doing so, affect their physical and mental health, resilience, finances, employment opportunities, ability to have a life alongside caring and so on. Moreover, The *impact* of caring is the overriding factor in determining a carer's need for support. A recent study³ shows that many people providing over 35 hours of caring each week do not receive practical support and some stop work or retire early to care. In some cases, this is because the services for the cared-for person are not sufficiently flexible to allow the carer to continue in work.
- 8) Shifting the balance of care from institutional care to care at home or in a homely setting must not create an unmanageable burden on carers to the extent that their health and wellbeing are adversely affected thus impacting on their ability to care.
- 9) In many circumstances health inequalities and poverty will impact adversely on carers. The largest proportion of households with a carer (28%) are in the 20% most deprived data zones in the Scottish Index of Multiple Deprivation (SIMD).⁴ Many of these carers will have poor health. The same study mentioned in paragraph 7 above shows that more than four in ten carers (48%) have been in debt as a result of caring and more than five in ten carers (52%) said that financial worries affected their health. It is therefore important that local strategies, and the implementation of the proposed legislation, focus on tackling the health inequalities and poverty experienced by carers.
- 10) There are also carers who tend to be more "hidden" than others, including Black and Minority Ethnic (BME) carers and Gypsy/Traveller carers, or who might not be considered to be carers including carers of people with substance misuse issues and student carers.⁵ Kinship carers⁶ too can also

³ Carers UK (2013):The State of Caring (295 carers in Scottish sample) <u>http://www.carersuk.org/professionals/resources/research-library/item/3090-the-state-of-caring-2013</u>

⁴ Scottish Household Survey 2007-08

⁵ The Scottish Government does not collect data on the number of student carers in Further and Higher Education. However, based on four years of data from the Scottish Household Survey (in order to have a big enough sample), and taking into account those caring for over 35 hours a week, a very rough estimate is 2,300 student carers, both adult and young carers.

be carers if the child they are caring for is a child in need and/or if they care for someone else.

- 11) Additional years of healthy life will give the capacity for more caring by individuals if that is what they want to do. Equally, however, family migration patterns with people living apart from relatives (which can contribute to a decreasing ability or willingness to care), declining family size and increasing life expectancy could lead to a "deficit" in unpaid care, especially in rural and remote areas. This means that the availability of carers could pose a challenge as we move forward. It is important, therefore, not to further exacerbate the potential "deficit" position by not fully supporting the existing carer population.
- 12) The Scottish Government will continue to support carers and young carers through further policy and practice developments and by driving forward the ten Manifesto commitments in support of carers and young carers. A summary of these developments and the Manifesto commitments is at Annex C. Local authorities, Health Boards and the Third Sector also continue to support carers in practical and imaginative ways to improve carers" outcomes.

Programme of reform - other legislative provision

- **13)** More is being done to support carers in recent legislation and in Bills currently before the Scottish Parliament. The Social Care (Self-directed Support) (Scotland) Act 2013,⁷ (SDS Act) which is planned to come into force on 1 April 2014, provides a power for local authorities to support carers. This means that local authorities can support carers and young carers at their discretion. We consult in chapter 4 on whether this power should become a duty, linked to an eligibility framework.
- 14) Subject to it receiving Parliamentary approval and Royal Assent, the Children and Young People (Scotland) Bill⁸ will also support both carers of disabled children and young carers. This is because it will improve the way services support children and families by promoting the rights and wellbeing of all children through early intervention and cooperation between services with the child at the centre.

⁶ If a looked-after child cannot remain with their birth parents they can be placed by a local authority in the care of family or friends, for either a short or long period of time. Under the Looked After Children (Scotland) Regulations 2009, these 'kinship carers' are defined as "a person who is related to the child (through blood, marriage or civil partnership) or a person with whom the child has a pre-existing relationship".

⁷ <u>http://www.legislation.gov.uk/asp/2013/1/contents/enacted</u>

⁸ <u>http://www.scottish.parliament.uk/help/62233.aspx</u>

- **15)** The Public Bodies (Joint Working) (Scotland) Bill⁹ provides the legislative framework to support improvements in the quality and consistency of health and social care services through integration of health and social care.
- 16) Integration of health and social care in Scotland is about bringing together planning and delivery arrangements spanning Health Boards and the social care responsibilities of local authorities, with teams whose members are integrated in relation to their shared objectives. New integration authorities will be established, whose membership will be drawn from Health Boards and local authorities, and whose functions and resources will be delegated by Health Boards and local authorities.
- 17) Strategic planning lies at the heart of integration and is the mechanism via which integrated arrangements will be able to effect real improvements in service provision and outcomes. It will be particularly important that strategic planning for integrated functions and services works effectively within the broader context of Health Board and Council activity – effective integration is about partners and stakeholders across health and social care, and across the public, third and independent sectors, working together effectively, and with patients, service users and carers.

Role of carers' legislation

- 18) This wide programme of reform, including reform to community planning, will benefit Scotland spopulation, including carers and young carers. However, over and above this, there is a role for specific carers legislation which would be the nexus of support to carers and young carers. This consultation makes clear where support is being driven forward through other legislative routes and where carers legislation can make a further, meaningful difference.
- 19) There is a fundamental role for carers" legislation to accelerate the progress that has been made, to help ensure greater consistency in support for carers and young carers and to help achieve better and sustained outcomes. It is necessary to take forward an outcomes-based approach within the carers' legislation. This will provide a good fit with community planning and the outcomes-based approach being adopted more generally. Carers" legislation will also inspire renewed debate and ambition for what Scotland"s carers can expect.

Other initiatives which impact on carers

20) Equally, however, as we have made clear, carers" legislation cannot operate in isolation nor can it, on its own, transform the lives of all of Scotland"s carers. There needs to be better services and care packages for cared-for people. Welfare reform too, which is reserved to the UK Government, also has an impact. With regard to those areas of welfare reform where the Scottish Government has responsibility, Ministers are investing to support

⁹ <u>http://www.scottish.parliament.uk/parliamentarybusiness/Bills/63845.aspx</u>

vulnerable people. The current funding, along with proposals in the draft Budget, will result in an investment of at least £224 million¹⁰ over the period 2013-14 to 2015-16. This will help to limit the effects of the UK Government"s welfare reforms. The Carer"s Allowance (including level and eligibility rules) remains the responsibility of the UK Government.

- 21) The Expert Working Group on Welfare¹¹ established by the Deputy First Minister is now into its second phase of work and is looking at the policies and principles that would underpin a welfare system in an independent Scotland.
- 22) To accompany the SDS Act, we consulted on draft regulations and guidance on the waiving of charges for the support that carers will receive. The draft regulations were prepared to enforce the commitment made by Ministers during the Parliamentary process for the SDS Act that carers would not have to pay for the support provided directly to them under the SDS Act. The outcome of our consideration of the 46 responses received will be made known shortly. The Regulations will come into force on 1 April 2014.
- 23) Local authorities" existing charging policies are relevant to both carers and service users. It would not be appropriate in carers" legislation to change the charging policies of individual local authorities. COSLA"s charging guidance for non-residential social care services¹² aims to provide a framework to maintain local accountability and discretion whilst encouraging councils to demonstrate that in developing their charging policies they have followed best practice.

Preventative action

- 24) Together with the provisions in the Children and Young People (Scotland) Bill, the planned carers" legislation will improve outcomes for carers by making significant changes to the carer's assessment process, to preventative action and early intervention and to support for carers most in need. Carers should be able to access timely information and advice and other forms of early intervention to enable them to care for as long as they wish in good health and to have a life alongside caring.
- **25)** The Commission on the Future Delivery of Public Services¹³ ("Christie report") stated that support should be built around people and their communities. It is necessary to prioritise action to reduce demand for services in the longer run. An estimated 40 to 45 per cent of public spending in Scotland is focussed on

 ¹⁰ Includes Scottish Welfare Fund, £20 million to local authorities for Discretionary Housing Payments to help mitigate the impact on the "bedroom tax" and £7.9 million for advice and support services
 ¹¹ <u>http://www.scotland.gov.uk/Topics/People/welfarereform/EXPERTWORKINGGROUPONWELFARE</u>

¹² <u>http://www.cosla.gov.uk/sites/default/files/documents/13-01-</u> <u>25_item_xx_charging_guidance_for_non-residential_social_care_-</u> <u>charging_guidance_section_6_revised.doc_1.doc</u>

¹³ <u>http://www.scotland.gov.uk/About/Review/publicservicescommission</u>

meeting "failure demand" which is short-term spending aimed at addressing social problems. Therefore the imperative is to ensure that there are lasting and sustainable solutions.

- 26) Since carers can sometimes lack awareness of what is available to support them but can be fully supported by existing services in the community, it is important for health, social care and education professionals and those in the Third Sector to raise awareness with carers, especially if there is no need to "reinvent the wheel." Facilitating access to community-based resources will continue to be important.
- 27) Under the Children and Young People (Scotland) Bill the Named Person, and where appropriate, Lead Professional, will be key to raising awareness and supporting children, young people and families to identify and access appropriate services and support.

Financial issues

- 28) This consultation suggests a continuum of support for carers from the important first step of identification to a Carer"s Support Plan and support. There are pressing financial constraints on local authorities, Health Boards, the Third Sector and the Scottish Government. Within the financial constraints local authorities have to meet their statutory duties in relation to people in crisis. There are of course challenges in shifting investment to preventative measures of support. Important developments such as the self-directed support legislation and the Reshaping Care for Older People"s Programme Change Fund help to address these challenges. Any eligibility criteria or framework developed for support to carers should take account of the preventative approach.
- 29) As previously stated, despite the challenging financial climate which we now operate within, the Scottish Government remains committed to supporting carers and young carers, with significant investment provided over recent years. In addition, we will work with our key stakeholders throughout this process of consultation and in the lead up to the Parliamentary stages for the legislation to fully identify the costs associated with delivering the requirements within the carers" legislation. This will ensure that support to our carers and young carers is delivered in the most cost-effective way. We are fully aware too of Third Sector and statutory sector capacity issues that would need to be considered and taken into account.
- 30) A relatively modest investment of £5 million each year for NHS Board Carer Information Strategies has resulted in a lot of progress in supporting carers and young carers. Sometimes, however, this funding has become core funding for projects instead of achieving additionality. Nevertheless, the CIS funding shows what can be achieved: modest input resulting in good outcomes.

Evidence

- **31)** There is a strong evidence base demonstrating what can be achieved in supporting carers. Chapter 4 on Support to Carers refers to the beneficial impact of short breaks in supporting wellbeing. Moreover:
 - improved identification of needs and support to carers is likely to lead to savings in terms of public expenditure costs avoided;¹⁴
 - support to carers by a variety of different means can result in savings by preventing or delaying admission to hospital and residential care;¹⁵
 - effective local delivery of short breaks can result in financial savings to health and social care;¹⁶ and
 - the Social Return on Investment (SORI) associated with support to carers through carers centres is an estimated £73 million gain (based on five carers centres) for an investment of less than £5 million.¹⁷
- **32)** In summary, we see a key role for carers" legislation combined with other legislative provisions and continued policy and practice developments, to drive forward this important agenda in order to improve outcomes for carers and young carers. Carers save the Scottish economy over an estimated £10 billion each year.¹⁸ Without carers" and young carers" commitment the fabric of Scottish society would crumble. We collectively need to support carers and young carers further.

¹⁴ Overcoming Barriers: Unpaid Care and Employment in England (2012), London School of Economics and Political Science/NIHR School for Social Care Research (Linda Pickard et al) – public expenditure costs of working age carers leaving employment as a result of their caring role are £1.3 billion each year in England.

http://blogs.lse.ac.uk/healthandsocialcare/2012/04/25/dr-linda-pickard-public-expenditure-costs-ofcarers-leaving-employment/

¹⁵ Yeandle S & Wigfield A (eds) (2011) - New approaches to supporting carers" health and well-being: Evidence from the National Carers" Strategy Demonstrator Sites programme <u>http://www.sociology.leeds.ac.uk/assets/files/research/circle/151111-6121-circle-newapproaches-</u> <u>complete-report-web.pdf</u>

¹⁶ NEF Consulting (2009) The Social and Economic Value of Short Breaks <u>http://www.lx.iriss.org.uk/content/social-and-economic-value-short-breaks</u>

¹⁷ Clifford, J. et al (2011) The Princess Royal Trust for Carers: Social Impact Evaluation using Social Return on Investment, London, The Princess Royal Trust for Carers http://www.carers.org/sites/default/files/prtc draft report v7 final version 3 with edits.pdf

¹⁸ Buckner, L & Yeandle S (2011) Valuing Carers <u>http://www.carersuk.org/professionals/resources/research-library/item/2123-valuing-carers-2011</u>

Chapter 2

The Carer's Assessment (the Carer's Support Plan)

Summary

This chapter discusses a number of proposed changes to the carer's assessment process which are relevant once carers are identified. Chapter 8 covers carer identification.

The changes are designed to improve take-up and reach of the carer's assessment (renamed Carer's Support Plan), to achieve a personal outcomes focus for carers and to ensure a straightforward, tailored process.

The new Carer's Support Plan would not apply to young carers whose wellbeing needs should be considered within the Getting it Right for Every Child (GIRFEC) approach and who may be eligible for the Child's Plan under the Children and Young People (Scotland) Bill.

This chapter also sets out issues about the portability of assessment and seeks views.

Introduction

- 1) Under the existing law,¹⁹ carers who provide a substantial amount of care on a regular basis are entitled to a carer's assessment. This applies whether or not the carer is a child. Carers request the local authority to make an assessment of their ability to provide care. The cared-for person must appear to the local authority to be a person for whom they must or may provide community care services or children's services. Local authorities must also notify carers that they may be entitled to receive a carer's assessment.²⁰
- 2) The carer's assessment is the gateway to potential support for the carer. Carers should have the opportunity to discuss their need for support to enable them to achieve the personal outcomes they desire.
- 3) Over the years, local authorities have adopted many different approaches to the undertaking of the carer's assessment. Some carry out the carer's assessment themselves whilst others delegate this function, in whole or in part, to Health Boards or to the Third Sector.²¹ Some take account of the guidance on interpreting a "substantial amount of care on a regular basis"²²

¹⁹ Section 12AA of the Social Work (Scotland) Act 1968 and section 24 of the Children (Scotland) Act 1995

²⁰ Section 12AB of the Social Work (Scotland) Act 1968 and section 24A of the Children (Scotland) Act 1995
²¹ Local authorities have neuron under section 4 of the 1008. Act to inverte at the theory of the section of t

²¹ Local authorities have powers under section 4 of the 1968 Act to involve other bodies or persons in helping them to carry out their functions, and may delegate functions to Health Boards in accordance with section 15 of the Community Care and Health (Scotland) Act 2002.

²² Carers: Community Care and Health (Scotland) Act 2002, Guidance on sections 8-12, Scottish Executive Circular CCD 2/2003 <u>http://www.sehd.scot.nhs.uk/publications/cc2003_02full.pdf</u>

whilst others do not. Some have lengthy carer's assessment forms and others have shorter forms. Some call the carer's assessment by that name whilst others have different names such as the Carer's Support Plan. Some assess a carer whilst others have a conversation or journey. Some have introduced self-assessment for carers and others have not.

- 4) Some authorities provide low-level support to carers without a carer's assessment in order to provide a quick form of preventative support. However, as the carer is still being asked questions in order to determine need and outcomes to be achieved, this is really a light-touch assessment.
- 5) Presently, the carer's assessment is not the only form of assessment for carers. Carers can be assessed with cared-for persons through the community care assessment. They can be assessed separately or in conjunction with an assessment of the person they care for.
- 6) *Talking Points: A Personal Outcomes Approach*²³ is a driver for continuous improvement in achieving good outcomes for carers through the carer's assessment.
- 7) There nonetheless remain concerns about both the number of carer's assessments undertaken and the quality of assessments. Whilst the Scottish Government does not collect data on the number of assessments carried out we do know from a variety of sources²⁴ that numbers are relatively low, compared with the number of people who are identified as carers. However, this will vary across the country. Moreover, some identified carers do not want a carer's assessment.
- 8) More can be done through continuous policy and practice improvement to build on the quality and numbers of assessments. We do see merit though in making some changes through law.

Change name of the carer's assessment to the Carer's Support Plan

9) Some carers, including those who are new to caring, feel stigmatised by the use of the term, "carer's assessment." The idea of "assessment" has connotations of judgment and stigma. We propose therefore to change the name to the Carer's Support Plan.

Removal of substantial and regular test

10) Some local authorities undertake an assessment to decide if carers care on a regular and substantial basis. Some do not. We propose to remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan. This will reduce any extra work amongst those authorities that do make a decision on whether a carer cares on a regular and

²³ <u>http://www.jitscotland.org.uk/action-areas/talking-points-user-and-carer-involvement/</u>

²⁴ eg Change Fund Plans; note from Carers Trust Learning Exchange, October 2013

substantial basis. There will be greater consistency in approach to eligibility for the Carer's Support Plan. Carers will be put on the same footing as service users in terms of access to an assessment (Carer's Support Plan).

11) With the removal of the regular and substantial test, the duty to prepare a Carer's Support Plan will apply to a wider group of carers including those who have some caring responsibilities but who might not have particular difficulties or needs connected with those responsibilities at a particular point in time. We expect that carers who do not want a Carer's Support Plan will self-select themselves out of the process. For other carers who prefer to have a Carer's Support Plan but whose caring is not having a big impact on them, we would expect a light-touch Carer's Support Plan with potentially low-level preventative support being offered, including effective signposting to community supports. Carers" needs can however change guite dramatically in a short space of time and it is important to keep the Carer's Support Plan under review. We propose that statutory guidance will set out differing types of Carer's Support Plan that can be taken forward with the carer. The aim is to have a Carer's Support Plan which is carer-friendly. personalised, outcome-focussed, light-touch where necessary and more rigorous as required.

Removal of other existing criteria

- 12) We propose removing that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children's services. This is because cared-for people don"t always need or receive such services, or they might refuse them. Moreover, they might have medical needs only. This includes children with medical needs who do not receive local authority support.
- 13) We propose to retain the requirement that the carer may request a local authority to make an assessment (Carer's Support Plan). However, since not all carers will know to request a Carer's Support Plan, we propose also to introduce a requirement that a local authority must offer a Carer's Support Plan. This means that there would be two possible routes through to the Carer's Support Plan.
- 14) We propose to remove the wording in existing law that the carer's ability to provide care is being assessed. The term, "ability to care" has sometimes been interpreted to imply a negative view of the carer"s competence or skills. This is clearly not the case. Instead, we will introduce an outcomes-based approach so that the Carer"s Support Plan must consider the outcomes that the carer wishes to achieve both in day-to-day life and in the future. These outcomes are likely to relate principally to being able to maintain and manage the caring role and having a life alongside caring.
- 15) We do not propose to include in the new law a list of issues that the Carer's Support Plan must include. By having a list, it might be construed as a "tick-box" exercise. We do, however, propose to have statutory

guidance covering a wide range of issues appropriate for a Carer's Support Plan to include: taking into account the carer's willingness to continue caring, whether the carer works or wishes to do so, emergency and future planning and so on.

Timescales for carrying out the Carer's Support Plan

16) There is some evidence that it can sometimes take quite a long time for carers to be offered a carer's assessment and/or to be reassessed. We have ruled out introducing timescales for the undertaking of the Carer's Support Plan as this must be determined locally. Instead, we propose to introduce a duty for local authorities or other bodies carrying out the assessment process to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time to be advised of the reasons.

Other forms of assessment

- **17)** There is sometimes a lack of clarity for both practitioners and carers as to why there is a separate carer's assessment. This is because sometimes the carer's needs can be met if they are assessed with the cared-for person as part of the community care assessment. Indeed, the relationship between the carer and the cared-for person can point to one assessment covering both as the way forward. This might suit some people. However, some carers assessed through this route are clear that the main focus is the cared-for person and they are sometimes even unaware that they have been assessed themselves. Moreover, recent research (covering three local authorities) indicates that a separate focus on the carer can be lower down the priority list for local authorities in comparison with work that is done with the cared-for person.²⁵
- 18) Some parent-carers of disabled children in particular would however favour what they call a family-based assessment so that the needs of the whole family unit can be assessed and addressed. Whilst we understand the point made, it would be difficult to legislate for a type of assessment which covers both individual and common needs, actions, outcomes and so on. Assessments for each member of a family can however cross-reference each other and could be carried out by the same professionals at the same time if that suited the requirements of those involved. Moreover, under the Children and Young People (Scotland) Bill, the Child"s Plan for children with a wellbeing need will need to take into account, where reasonably practicable, the child"s parents views. Parent-carers will of course be eligible for a Carer"s Support Plan in the same way that they are currently eligible, if they are a regular and substantial carer, for a carer"s assessment.

²⁵ Carer"s assessment and outcome focussed approaches to working with carers: A joint project between Midlothian Council Community Care Team and VOCAL Midlothian Carers Centre, 2013 (CRFR/IRISS)

http://www.vocal.org.uk/assets/files/downloads/PROP%20Report%202013.pdf

19) It is important that a Carer's Support Plan is offered so that the carer's needs are identified in their own right and the carer is supported to identify and achieve their own personal outcomes. Rather than the carer's needs being assessed with those of the cared-for person as part of one community care assessment we would suggest that the Carer's Support Plan can be considered at the same time as a section 12A community care assessment or Child's Plan if the carer and cared-for person agree to this.

Role of the Third Sector

- **20)** Local authorities have the statutory responsibility for carrying out the carer's assessment although other bodies can be involved. Local authorities however ultimately remain statutorily responsible for the overall performance of the assessment.
- 21) Some local authority areas over the past few years have witnessed a maturation in the relationship between the council and the Third Sector, including carers" centres, with regard to carrying out the carer's assessment. In the Borders, for example, the carers" centre is the only body carrying out the carer's assessment, and this has led to stronger working relationships with the local authority at strategic and practitioner level.
- 22) As noted in the footnote to paragraph 3 there is already statutory provision allowing local authorities to arrange for the Third Sector to assist in the performance of their functions. There is no need therefore to introduce any other provision. We will however make clear in statutory guidance that the local authority can use the existing legal provisions to involve the Third Sector in the undertaking of the Carer's Support Plan.

Young carers

23) The proposals for the Carer's Support Plan outlined in this chapter do not apply to young carers. Young carers should instead have their wellbeing assessed within the GIRFEC framework and with consideration being given as to whether they require a Child's Plan under the Children and Young People (Scotland) Bill.

Portability of Assessment

- 24) There are issues to be addressed about the portability of assessment, primarily for service users (adults and children) but also for carers. This means considering the assessment process when people move from one local authority area to another to change jobs or to live closer to each other or for another reason. Gypsies/Travellers may also face similar issues when they move from one local authority area to another.
- 25) There will always be variability of service in different local authority areas. Each local authority in Scotland is required to determine the best mix of service in its area to meet the needs of local residents. There are duties on

local authorities to assess and to respond to the needs of people who are ordinarily resident in their areas.^{26 27} As a result of this duty, there is inevitable variation in the types of services available to residents in each area. These are influenced by a number of factors such as the dispersion of population, physical geography, the availability of trained staff and local attitudes to different types of care. There will also be variations in charging policies from one area to another, dependent on a wide range of factors. Whilst local democratic decision-making and accountability is important, there is scope for improvement to the consistency of services and support.

- 26) Service users and carers may experience frustrations about assessment when moving from one area to another. If some parts of the service user's care and support package are interrupted until a new assessment is carried out, then this is a cause for concern as is any requirement to repeat their history and experiences in order to access services and support.
- 27) With regard to carers, if a service user moves local authority area to be closer to the carer, the carer might need a new Carer's Support Plan to take account of the new caring arrangement, for example, there might be less travelling required but more *in situ* caring being undertaken.
- 28) We are of the view that improvements can be made to the assessment process in order to make it easier for service users and carers to move from one part of the country to another. Therefore, the Scottish Government and COSLA, with relevant interests, will work together to take this forward. We will be able to consider issues about improved cooperation, communication and protocols between local authorities, and access to as much information as possible before any move takes place about the availability of services and support in the new local authority area.
- 29) For young carers the transfer of their Child"s Plan will be governed by the legislation and guidance relating to the management and transfer of Child"s Plans. The Child"s Plan will support the statutory provisions and duties in relation to other children"s plans such as looked after children"s plans and coordinated support plans that may include planning to address the wellbeing needs of a young carer.

²⁶ Ordinary Residence Guidance was updated and amended in April 2010 and is set out in Circular CCD 3/2010 and associated regulations. The guidance aims to improve portability of care by introducing transitional arrangements for paying for care when an individual moves from one local authority to another. The guidance will be kept under regular review and will be amended as required to reflect policy changes eg integration of health and social care and self-directed support. http://www.scotland.gov.uk/Resource/0041/00411384.pdf

²⁷ Section 86 of the Social Work (Scotland) Act 1968 deals with recovery of expenditure between local authorities in a number of circumstances involving moves between areas.

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?

Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children^s services?

Question 4: Should we introduce two routes through to the Carer's Support Plan – at the carer's request and by the local authority making an offer?

Question 5: Should we remove from statute the wording about the carer's ability to provide care?

Question 6: Should we introduce a duty for local authorities to inform the carer of the length of time it is likely to take to receive the Carer's Support Plan and if it exceeds this time, to be advised of the reasons?

Question 7: How significant an issue is portability of assessment for service users and carers?

Question 8: Should the Scottish Government and COSLA with relevant interests work together to take forward improvements to the portability of assessment?

Chapter 3

Information and Advice

Summary

This chapter covers:

- carers' and young carers' access to information and advice, including to the Carers/Young Carers Rights Charter; and
- maintenance of information.

The aim is to complement existing and new policy and practice developments with provisions in law which would help to ensure that carers and young carers have access to comprehensive, accessible and carer-friendly information and advice so that they can then make decisions about what further support might be necessary. Information and advice for young carers should be tailored to be age-appropriate. Access to accurate and timely information and advice is empowering for carers and young carers and helps to promote and achieve positive outcomes. Information and advice is a form of support which should be available on a universal, preventative basis.

Introduction

1) Caring Together states:

"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."

- 2) Carers tell us that access to relevant and accessible information and advice is key to supporting them and the individuals they care for. Indeed it can be the golden key which then opens the door to further support. The provision of information and advice is important when someone is new to caring and at relevant points throughout the caring, including at transition points and as the nature or intensity of caring changes.
- 3) Lack of accessible and comprehensive information and advice both about services for service users and support for carers can be costly both in terms of future crisis management and the health outcomes of both carers and the individuals they care for. Carers sometimes tell us that the information they get comes too late or is not the right level of information. They say that their outcomes would be much better if only they had access to the right information at the right time.

4) This is summarised well in recent research:²⁸

'Both staff and carers felt that finding and giving information about services and resources (particularly local ones) was a challenge, **yet knowledge and information were considered to be crucial enablers for the achievement of personal outcomes.** Carers especially valued effective signposting from professionals to enable them to navigate the complex systems of health and social care with greater ease, but also felt this could be improved. Carers also suggested that information giving techniques could be improved, for example by revisiting information with someone once it has been given. These implications are relevant to all organisations, but it is likely that effective joint working and further development of information systems and provision to the public might be key enablers."

- 5) There is an important point about information-giving techniques. Some social work and health staff will say that relevant, helpful information has been passed on to the carer but it has not been understood or accepted. When carers are under a lot of stress and pressure, their ability to absorb and make sense of information will be impaired and that is why it is so important to deploy effective information-giving techniques.
- 6) The same applies to signposting and the provision of advice. The Carers Reference Group which advises the Scottish Government has made clear that carers can feel let down or abandoned by signposting which is ineffective. Sometimes the signposting needs to take the form of helping the carer on a one-to-one basis to navigate through the system to appropriate supports and services.
- 7) The availability of relevant and easily accessible information and advice is key to a preventative approach to supporting carers. This support ensures that carers feel informed and prepared and minimises the likelihood of caring relationships descending into crises.

Further policy and practice developments

8) Some of the funding the Scottish Government provides to Health Boards for Carer Information Strategies has supported the provision of information and advice. This has been helpful in providing a wide range of information and advice to carers.

²⁸ Carer"s assessment and outcomes focused approaches to working with carers. A joint project between Midlothian Council Community Care Team and VOCAL, Midlothian Carers Centre, 2013, CRFR and IRISS

http://www.vocal.org.uk/assets/files/downloads/PROP%20report%20summary.pdf

Information Point

Living it Up^{29} is a three year programme working with five local partnerships across Scotland aimed at empowering people to improve their health and well-being. Living it Up will deliver innovative and integrated health, care and wellbeing services, information and products via familiar technology enabling people to keep better connected with their communities and those they care for and receive care from. These technologies will include TV, mobile phone, games consoles, computers and tablets. The five partnership areas are: the Western Isles, Forth Valley, Lothian, Moray and Highland/Argyll & Bute. It is initially aimed at the over 50s but will also be of benefit to people living with long-term conditions, carers and those who just want to keep healthy, happy and safe.

Living it Up will provide a personalised and integrated menu of services, information, products and social activities to support social, health, care, and personal interests which will keep people connected, creating and sustaining relationships with family, friends, neighbours, local communities and health and care professionals.

Care Information Scotland³⁰ is being redesigned to provide information and advice for carers and those being cared for across Scotland. The service will provide information both nationally and locally. This service aims to enhance other information which is already available. It is proposed that the service will be operational from December 2014.

Existing legal provisions on information and advice

- 9) Presently, there is statutory provision which requires local authorities to notify carers that they may be entitled to request a carer's assessment.³¹ With regard to Health Boards, Scottish Ministers may require Health Boards to prepare and submit to them a Carer Information Strategy for informing carers who appear to the Board to be entitled to a carer's assessment that they may have such rights.³²
- 10) There are also provisions in law requiring local authorities to provide service users with information³³ and also to publish information, for example, about relevant services they provide in respect of children.³⁴
- The Patient Rights (Scotland) Act 2011³⁵ also contains provisions about 11) providing information to patients and the provision of patient advice and support services.

²⁹ https://portal.livingitup.org.uk/

³⁰ http://www.careinfoscotland.co.uk/home.aspx

³¹ Section 12AB of the Social Work (Scotland) Act 1968 and section 24A of the Children (Scotland) Act 1995 ³² Section 12 of the Community Care and Health (Scotland) Act 2002

³³ For example, section 12A(4)(b) of the 1968 Act ³⁴ Section 20 of the Children (Scotland) Act 1995

³⁵ http://www.legislation.gov.uk/asp/2011/5/contents/enacted

- 12) The Social Care (Self-directed Support) (Scotland) Act 2013 includes duties for local authorities to provide information to adults, children, carers and young carers about self-directed support in relation to the four options available to service users and carers.³⁶
- **13)** There are provisions in the Children and Young People (Scotland) Bill³⁷ for service providers to communicate information about the role of Named Persons and help the child, young person or their parent to access a service or support.

Proposals for new legislative provisions

- 14) Although there are policy and practice developments underway to support service users and carers with information, our view is that further impetus should be given through law to the provision of both information and advice. There would be suitable dovetailing between new information developments and those proposed in law. Moreover, the only provisions presently in law with regard to the provision of information directly to carers relate to the specific areas of the carer's assessment and the options under self-directed support.
- 15) We therefore propose to introduce a duty for local authorities to establish and maintain a service for providing people in its area with information and advice relating to the Carer's Support Plan, support for carers and the Carers Rights Charter. (Annex D provides further information on the Carers Rights Charter). We also intend that the information and advice must be accessible to, and proportionate to the needs of, carers. Information should be provided about support to carers provided by the Third Sector.
- **16)** We envisage that the provision of information and advice will be available to all carers whether or not they have received a Carer's Support Plan.
- 17) We will set out in statutory guidance the level and type of information and advice that is to be available through the service. We envisage a service which, amongst other things, takes account of different caring roles, which provides information and advice on, or signposts carers to, services on welfare benefits checks/income maximisation, and which provides information advocacy for carers and short breaks.
- 18) We also propose to repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer Information Strategies to Scottish Ministers. Our view is that the provision will be redundant when the integration of health and social care is established. Subject to Spending Review decisions, the Scottish Government would still be

 ³⁶ Sections 9 and 10 of the Social Care (Self-directed Support) (Scotland) act 2013
 ³⁷<u>http://www.scottish.parliament.uk/S4_Bills/Children%20and%20Young%20People%20(Scotland)%2</u>
 <u>0Bill/b27s4-introd.pdf</u>

able to provide funding towards the costs of information and advice services and for the other forms of support to carers provided by Carer Information Strategies. Indeed, the role of Health Boards has been crucial in developing support to carers and young carers and we would like to see this maintained.

Young carers

19) The proposals for changes in the law about information and advice should apply to young carers in the way they apply to adult carers (but for information and advice on the Carers" Support Plan, read Child"s Plan). There would need to be appropriate dovetailing with information provided under the Children and Young People (Scotland) Bill and the Education (Additional Support for Learning) legislation.

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 7: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?

Question 8: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?

Chapter 4

Support to carers (other than information and advice)

Summary

This chapter seeks views on whether we should retain the discretionary power to support carers in the Social Care (Self-directed) Support Act 2013 or whether we should repeal that provision and introduce a duty to support carers within the context of an eligibility framework.

We also seek views on introducing provisions about short breaks.

Introduction

1) Presently, there are no provisions within social care law to directly support carers. Where local authorities support carers directly now, they are using the power to advance wellbeing in section 20 of the Local Government in Scotland Act 2003.

Discretionary power to support carers

- 2) As from 1 April 2014, local authorities will have a *discretionary power* to support carers when the Social Care (Self-directed Support) (Scotland) Act 2013 comes into force. The local authority must carry out a carer's assessment, consider the assessment and then decide whether the carer has needs in relation to the care provided to the cared-for person. If the local authority decides that the carer has needs, the authority then has to consider whether the needs could be satisfied (wholly or partly) by the provision of support and decide whether to provide such support. The support is then provided to the carer by one of the four options for self-directed support set out in the legislation. Young carers too are eligible for support in similar fashion.
- 3) As stated, the power is discretionary. It might be used in relation to existing carers who receive support and to some new carers. It might be used to support carers in crisis or who are deemed to have critical or substantial needs. It might also be used to support carers on a preventative basis to help ensure that they can continue caring in good health and to have a life alongside caring. We envisage that the type of support provided directly to carers using this power would mostly be short breaks but could also include advocacy, help with the cost of transportation, driving lessons, leisure activities, counselling and anything that helps promote positive outcomes for carers. Other types of support such as information and advice would generally be provided universally in any event.

- 4) The first option is to maintain the status quo by retaining the discretionary power to support carers and young carers as it stands. Duty to support carers
- 5) Another option is to repeal the power to support carers and to introduce instead a *duty* to support carers. However, it would not be possible, realistic or desirable for local authorities to support all carers. Therefore, the duty would need to be linked to an eligibility framework. This means that local authorities would be required to support carers on a consistent basis across the country, but allowing for local variation in the type of support available and in accordance with an eligibility framework. The eligibility framework would be set out in regulations or guidance rather than in primary legislation. This would give flexibility for the eligibility framework to be amended from time to time after consultation.
- 6) With the introduction of an eligibility framework, it would have to be accepted that the carer's needs could be met (wholly or partly) by the provision of services to the cared-for person. We have evidence through the Reshaping Care for Older People Programme Change Fund that carers' needs can be met though support to the cared-for person. However, this would need to be agreed through the Carer's Support Plan and it is most certainly the case that the carer's needs for support can often be met by direct support to the carer. Indeed, it will often be a combination of direct and indirect support which will result in the best outcomes for carers.
- 7) Any duty to support carers would herald an approach similar to that used for the people they care for. An important point, where carers are being supported directly, is that the costs of doing so are relatively modest. For example, help with gardening, gym membership, buying a laptop to keep in touch with family and friends are low-cost interventions to help the carer look after his or her own health and wellbeing. Some types of support will cost more but should help the carer to care for longer in better health and to avoid breakdown or crisis.
- 8) The second option is to introduce a duty for local authorities to support carers according to an eligibility framework and by either direct support to the carer and/or by the provision of services to the cared-for person.

Duty to support young carers

- 9) Under the Children and Young People (Scotland) Bill, there will be a duty on Health Boards and local authorities to promote, support and safeguard the wellbeing of children. Where there is a concern about any aspect of wellbeing, the Named Person will start a process to identify and assess wellbeing needs and put in place appropriate support to improve wellbeing outcomes.
- **10)** In some cases a child with a wellbeing need may require a targeted intervention which is the provision of a service directed at meeting the needs

of children whose needs are not normally capable of being met, or met fully, by the services which are provided generally to children by the authority.

- 11) The Child"s Plan will not determine eligibility for support. Rather, access to support will be determined by the needs and circumstances of individual children. This means, in effect, that young carers could access support whether or not they have a Child"s Plan. We envisage that the circumstances where young carers do not have a Child"s Plan will be rare. Support to young carers not provided through universal services will be agreed and recorded in the Child"s Plan.
- 12) Some young carers are likely to require support through a targeted intervention. If we introduce a duty within carers" legislation for local authorities to support young carers according to an eligibility framework, the support would in effect be a targeted intervention. The eligibility framework would need to be consistent with GIRFEC principles and values.
- 13) This type of targeted intervention could allow young carers access to self-directed support, including direct payments in order to help promote their health and wellbeing so that they can care in good health and maintain their childhood.
- 14) If a duty to support carers and young carers is introduced, we would also expect that local authorities would have a discretionary power to support carers and young carers where they do not meet the criteria for the eligibility framework.

Short breaks

- **15)** One of the most sought-after and important interventions to support carers and young carers and the people they care for in order to achieve good outcomes is short breaks. By short breaks, we mean any provision which supports carers and young carers to have time out from caring in order to recharge their batteries. The short break can include holidays, time out for leisure activities, time to meet up with friends and breaks away together. Sometimes the short break is an activity for the cared-for person which the carer joins in, or an activity exclusively for the cared-for person.
- **16)** There is evidence that carers who did not receive a break in a recent demonstrator pilot in England were more likely to show deterioration in wellbeing scores.³⁸
- **17)** There has been progress in Scotland in rolling out short breaks provision but it remains patchy with variation across geographic areas and care groups.

³⁸ CIRCLE, New Approaches to supporting carers" health and wellbeing: Evidence from the National Carers Strategy Demonstrator Sites, University of Leeds, 2011 <u>http://www.sociology.leeds.ac.uk/assets/files/research/circle/151111-6121-circle-newapproaches-complete-report-web.pdf</u>

- 18) We could consider introducing a duty for local authorities to provide and promote short breaks. This would be by means of a duty to provide short breaks services in the area which would be available to eligible carers or to the people they care for. One argument against this apart from the important issue of cost is that any power or duty to support carers already takes account of short breaks" provision within it, without naming it as such. Moreover, it could be argued that short breaks provision is an input to produce an outcome of improved carer health and wellbeing, so why concentrate on an input. Finally, not all carers want short breaks.
- 19) Set against this, a duty to provide short breaks could dovetail with a power or duty to provide other forms of support which are not specified. A duty could provide a great opportunity for innovation to tackle specifically the key concern about lack of adequate, personalised, life-changing provision meeting the needs of carers and the people they care for.
- **20)** Any duty could specify that local authorities publish and promote a Short Breaks Statement, an explanation of what people could expect, eligibility criteria and how the range of services offered (including those universal community-based ones) is designed to meet the identified needs.
- 21) We might expect that establishing a duty with regard to short breaks would be costly. We would need to undertake financial modelling before we introduced any legislative duty.
- 22) A duty with regard to short breaks" provision could be desirable as short breaks" provision can be seen as an "add-on" when in fact it often produces very good outcomes for carers. With a considerable amount of innovative thinking, services can potentially be reconfigured in order to provide for such a commitment. Some services can be underutilised with a silo approach to provision for different care groups which is not always efficient or effective. A duty could act as an incentive to develop the market in order to provide the short breaks.
- 23) We would like to invite views on a duty with regard to short breaks.

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 9: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?

Question 10: Alternatively, should we retain the existing discretionary power to support carers and young carers?

Question 11: Should we introduce a duty to provide short breaks?

Chapter 5

Stages and Transitions

Summary

This chapter discusses:

- stages in the experiences of the cared-for person and carer;
- transition from children's services to adult services for young people; and
- transition from being a young carer to adult carer.

We propose provision in law for early planning and the preparation of a Carer's Support Plan (which would take effect if the young carer becomes an adult carer after his or her 18th birthday).

All other stage and transition issues discussed in this chapter are covered in existing policy and practice, existing legislation or will be covered in future guidance.

Introduction

- 1) Often the terms "stages" and "transitions" are used interchangeably. For the purposes of this consultation we draw a distinction between stages and transitions as follows:
- stages relate to different stages experienced by cared-for people and carers. For example, one new stage relating to cared-for people is the development of a new health condition over and above the one they already have and the management of this. The carer too will often be involved in the management of the conditions. One new stage for carers is caring for more hours each week due to the rapid deterioration in health of the person they are caring for;
- <u>transitions</u> mean transition of service for cared-for people usually required because of the cared-for person"s age. The transition is within a service or services especially health, social care and education. It is primarily between children"s and adults services for young people.

Stages

- 2) Carers tell us that they can experience difficulties and challenges at different stages in their caring role. Where these challenges are about managing a change in relation to the person they care for this can have an impact on both the cared-for person and the carer.
- **3)** The impact can be negative causing disruption and upheaval. For example, where the management of new medication for the cared-for person is not

handled well by services, this can cause anxiety and stress for both the cared-for person and the carer.

- 4) Where there is poor planning before a young adult with learning disabilities moves from home to supported accommodation, the cared-for person and carer can both experience considerable stress.
- 5) Sometimes the impact is positive in that there is a new and exciting opportunity for the cared-for person, for example, a new volunteering opportunity or paid employment for a disabled young person.
- 6) Where the planning in relation to a move into supported accommodation is good, the young adult with learning disabilities and carer often look forward to this new phase in both of their lives.
- 7) Carers and young carers also directly experience different stages of caring. These are many and varied and include:
 - managing new equipment and medication for the cared-for person;
 - coping with changing relationships;
 - dealing with increasingly challenging behaviour;
 - a change in the employment status of the carer whilst in the caring role;
 - managing their own changing health and personal circumstances; and
 - the end of caring.
- 8) In these circumstances consideration should be given by the carer and the local authority to the appropriateness of an updated Carer's Support Plan for adult carers and Child's Plan for young carers and the provision of support to carers and young carers.

Information Point

As set out in chapter 2 we propose to issue **statutory guidance** on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on *managing stages of caring*. This will apply to adult carers only. Guidance under the Children and Young People (Scotland) Bill on the Child's Plan will include guidance for those undertaking the Child's Plan about *managing stages of caring* where the carer is a young carer.

Transitions

9) Transitions involving a change in service for young people from children"s services to adult services need to be managed well and handled sensitively in a personalised manner. In order to improve outcomes, people need to experience better transitions including the transition from paediatric to adult health services and from children"s social work services to adult social work services.

10) It is important that all cared-for people, especially people with complex needs, experience good transitions. Good transition planning also applies of course to people living independently.

Information Point

Some young people, including some disabled young people and some young people with caring responsibilities *who are also service users themselves*, will need continuing *services* into adulthood. To help support transition, subject to Parliamentary approval of the Children and Young People (Scotland) Bill, we are proposing to issue **statutory guidance** under that legislation. This will indicate the type of transition activity that might be required. In the context of a Child"s Plan, the longer term outcomes for children and young people should explicitly include issues around transition from children"s services into adult services where the absence of planning considerations could have an adverse impact on the young person.

The Named Person³⁹ or Lead Professional⁴⁰ for the child, where one has been appointed, should consider whether the wellbeing needs of the child on transition to adult services require a child"s planning meeting. Consideration also needs to be given to appointment of a person to manage the Carer"s Support Plan on transition to adult services.

Information Point

Self-directed support is an important mechanism for delivering services and has a part to play in transition issues for service users, including disabled children. For example, a budget for young people early on (age 14 or so) would provide them with control over a notional budget (in the form of an individual service fund) or a real budget (in the form of a direct payment) and then would support them to purchase a range of support options with that budget. A good transition involving a SDS approach involves the carers managing integrated support packages with a transparent budget up to the age of 16 and then as the young people reach age 16 to 18 they themselves gradually take control of the budget. One benefit is the opportunity to build the assets and capabilities of the young people by way of a person-centred and outcomes-focused approach.

Please see the work of the Scottish Transitions Forum.⁴¹ They have also published a report on the role of SDS in helping to improve transitions.⁴²

³⁹ Under proposals in the Children and Young People (Scotland) Bill), every child from birth until they reach age 18 or older if still at school will have a Named Person made available to them.

⁴⁰ Under (GIRFEC) where concerns about wellbeing require coordinated intervention from more than one service or agency, then a Lead Professional will be identified to take on that coordinating role. ⁴¹ http://scottishtransitions.org.uk/

⁴² Principles of Good Transitions Planning, Improving transitions for young people with Additional Support Need (Scottish Transitions Forum) ARC Scotland

11) Any transition of cared-for people from adult services to older people"s services is different from transition from children"s services to adult services as the legal framework within which the local authority supports service users, including cared-for people, does not change at age 65. Indeed in most instances there will be no transition issue as services should be delivered based on need. Younger adults with complex needs might need a similar care package as an older person with such needs. We do recognise however that there are challenges which need addressing. These include providing appropriate services for people who do not conform to what might be termed "typical patterns," for example, people over the age of 65 who acquire a physical impairment. The integration of health and social care should help provide the solution.

Young carers who may become adult carers

- 12) The young person with caring responsibilities may also be receiving support to address a wellbeing need unrelated to caring. And/or they might be receiving support due to the impact of the caring on their wellbeing. We are however working to ensure that caring does not have a detrimental impact on the lives of young carers. Whatever the circumstances, the Child[®]s Plan might include planning, where required, on transition to adult services where the young person with caring responsibilities has a wellbeing need.
- 13) Some young carers will be supported by the Education (Additional Support for Learning) Act 2004 (as amended) which sets out the action that education authorities must take at various transition points in a child"s or young person"s school career, including the transition to post-school destinations.⁴³ Young carers are also further supported by the Post-16 Transitions Policy and Practice Framework: *Supporting all young people to participate in post-16 learning, training or work.* This Framework clarifies the expectations for delivery and the roles and responsibilities for the partners involved in supporting all young people in learning so as to progress towards and into work.⁴⁴
- 14) In order to ease transition from young carer to adult carer where such transition seems likely to happen there should be discussions between children"s and adult"s services, and the young carer, about any need for support as an adult carer. The Child"s Plan would be an appropriate place for this to happen where the absence of a transition plan for the move into adult services would impact on the young person"s wellbeing. This would be especially so if the lack of transition plan meant that the young person could not anticipate good health or having a life outside of caring. However, not all young carers will have a Child"s Plan due to them not all having a wellbeing

http://scottishtransitions.org.uk/scottish-transitions-forum-agenda-for-improvement-for-scottish-transitions/

 ⁴³ <u>http://www.scotland.gov.uk/Publications/2011/04/04090720/0</u> - Supporting Children's Learning – Code of Practice for Additional Support for Learning.

⁴⁴ <u>http://www.scotland.gov.uk/Publications/2012/11/3248</u> - Post-16 Transitions Policy and Practice Framework: *Supporting all young people to participate in post-16 learning, training or work*

need justifying the creation of a Plan. It is necessary to ensure appropriate support as an adult carer to enable continued caring (if that is what the carer wants) in good health and to have a life alongside caring.

- **15)** Where a young carer becomes an adult carer, as an adult carer he or she should have a Carer's Support Plan. In order to get this Plan, adult carers need to have discussions with services about the support needed to enable them to carry on caring whilst being able to meet their own aspirations and achieve good personal outcomes.
- 16) In order to ensure, therefore, that those young carers approaching the age of 18 who are likely to become adult carers receive a Carer's Support Plan to determine any need for support, we intend to make provision in law for dealing with this transition to adult carer. In doing so, we propose that young carers before they turn 18 will have a right to a Carer's Support Plan irrespective of whether or not they are receiving children's services. Whilst the discussions with the young carer would take place before the young carer's 18th birthday, any agreed support in the Carer's Support Plan would not take effect until the young carer becomes an adult carer. We do not propose a blanket approach that young carers have to be assessed at a certain age. This recognises that the best time to plan the move to support as an adult carer will be different for each young carer.
- **17)** The Child"s Plan is the key planning tool for dealing with transition from children"s to adult services. If, however, young carers on becoming adult carers need support in their role as providers of services to the people they are caring for, this should be agreed within the context of a Carer"s Support Plan. There is early planning for potential support to follow after the young carer"s 18th birthday. The young carer may of course already be getting support prior to their 18th birthday. This is not adding another tier of planning but ensuring that the planning works well for young carers who might become adult carers.

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 12: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on *managing stages of caring*? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).

Question 13: Should new carers" legislation provide for young carers to have a Carer's Support Plan if they seem likely to become an adult carer? Any agreed support recorded in the Carer's Support Plan would be put in place after the young carer becomes a (young) adult carer.

Chapter 6 – Carer involvement

- a) Service Design and Delivery
- b) Care Planning and Support

Summary

This chapter discusses:

- carer involvement in planning, shaping and delivery of services and support; and
- use of carer expertise and knowledge by professionals.

Arrangements will be made under the Public Bodies (Joint Working) (Scotland) Bill for the involvement by integration authorities of both service users and carers and carers' organisations in the planning and design of services through the strategic planning and locality planning processes. We do not need therefore to duplicate these arrangements in carers' legislation.

However, since not all services of Health Boards and local authorities will be within the scope of integration, we propose to make provision for involvement by carers and carers' organisations in planning, shaping and delivery of services and support in relation to services outwith the scope of integration where carers have an interest.

We also propose to establish a principle about carer and young carer involvement in care planning for the people they care for and support for themselves.

Introduction

- On a locality basis, it is clear that carers should be fully involved in the planning, shaping and delivery of services for the people they care for and support for themselves. The full involvement of carers in this way helps to deliver better quality services and support which are much more personalised and outcome-focussed.
- The Third Sector too carers organisations should be involved in an appropriate way.
- 3) Furthermore, at an individual level, the expertise and knowledge of the carer should be used effectively by health and social care professionals and by other professionals such as teachers, for example, in relation to disabled children.

Planning, shaping and delivery of services

4) As stated in *Caring Together*, the Scottish Government is committed to ensuring that carers are fully involved in the planning, shaping and delivery of services and support.

Information Point

One of the key principles of the voluntary sector short breaks fund is that there should be carer and service user involvement in the planning and delivery of the short breaks.

With regard to *Better Breaks*, funding should support the personalisation agenda, providing opportunities for carers and the children and young people they care for, to be at the centre of planning and decision-making about their short breaks. It takes a lot of work to ensure that this happens effectively and projects need to do more to ensure that this key principle is being met.

The evaluation of the first round of *Better Breaks* summarised the position well and has read-across to all carer and service user involvement:

"This principle could be viewed as "work-in-progress" and in particular around the involvement of children and young people. Often it was limited to "what the child wanted to do" at a session, usually from a menu of options rather than an inclusive model of working which put them at the heart of the project. However, some good examples did emerge. Conversely, some projects which were very focussed on involving children and young people in planning and delivery involved carers less.

The **gold standard** for personalisation would be for organisations to consider all the stakeholders and include them all in the planning, delivery and evaluation. In doing so, projects will be better able to anticipate and meet need alongside delivering lasting outcomes for carers and young people.⁴⁵

- 5) There has been progress in involving carers in strategic planning. The plans submitted for the Reshaping Care for Older People[®]s Programme Change Fund demonstrated progress in many local areas but with more to do in some areas.
- 6) The integration of health and social care will result in meaningful carer and service user involvement in the planning and delivery of services and support.

⁴⁵ Better Breaks, Evaluation Report on Round One of Better Breaks, April 2012 – March 2013, Dr Eleanor Logan

Information Point

The Scottish Government is to require, through regulations, that integration joint boards and joint integration monitoring committees have representation from carers. Guidance on strategic commissioning will make clear that the commitment extends to involvement in the design and delivery of future integrated services.

- 7) The integration of health and social care will mean that all adult health and social care services must be integrated. There is also flexibility for Health Boards and local authorities to integrate other health and social care services (for example, in relation to disabled children) where they agree to do so. Services for disabled children covering education are not within the scope of the Public Bodies (Joint Working) (Scotland) Bill although, where health and social care services for children are being integrated by local agreement, there will be local protocols for an interface between health and social care and education.
- 8) Carers should be involved in the design and delivery of support for themselves as well as in relation to services for the people they care for. We therefore propose to make provision for carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration.
- 9) We also propose to make provision for involvement by carers' organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration.

Carer involvement in care planning and support

10) Caring Together makes clear that carers are equal partners in care. Some of the work commissioned by the Scottish Government also uses this terminology. The "core principles for working with carers and young carers" developed by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC), EPiC (Equal Partners in Care)⁴⁶ states:

"Carers have a unique role in the life of the person they care for. When we are planning and delivering care for that person, it's important that we involve their carer. They have valuable knowledge to contribute and any decision will have an impact on their caring role. Carers, the person they care for and workers from health and social services should work together as partners to achieve better outcomes for all involved.

⁴⁶ http://www.sssc.uk.com/Educators-and-training-providers/better-outcomes-for-carers-and-youngcarers.html

Carers have the right to play an equal and active role in care planning and decisions. This does not mean that all carers are the same or that the caring is shared equally. Every carer has a different role, but the same right to have the support and information they need and to be involved as they choose to be."

- 11) The general principles set out in the Social Care (Self-directed Support) (Scotland) Act 2013⁴⁷ give expression to the full involvement of carers in the assessment of needs for support and the provision of support for themselves. Local authorities must collaborate with people in relation to assessment and the provision of support. A person must be provided with reasonable assistance in order that they can express their own views about the choices available to them and make an informed decision about their preferred choice. The principles apply to local authorities" social welfare responsibilities (the provision of care and support) for both adults and children.
- 12) The general principles in the SDS Act fully embrace what we would like to achieve in relation to carer involvement in their own assessment and decisions about support to themselves under the SDS Act. Moreover, existing legislation⁴⁸ also provides for local authorities to take account of the views of carers in the assessment of service users, both adults and children before reaching decisions on the services to be provided. The aim is to ensure that the care package meets the wishes and needs of both the cared-for person, and their carer as far as possible.
- 13) We propose that carers' legislation includes a principle about carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation.

Young carers

14) Young carers tell us that they sometimes like to be involved in the planning and delivery of services for cared-for people and support for themselves. However, their overriding concern is that their views are taken into account by professionals when decisions are made about the person they care for. This mostly, but not exclusively, applies to young carers aged from 14 to 17. Young carers have advised Ministers and local authority and Health Board representatives at the Young Carers Festival that they sometimes feel that health and social care professionals do not understand them. They also say that they are not always provided with information which they feel would not breach any confidentiality requirements. Nor have they been asked for their views on the care of their parent when they have been the sole family carer. We have sought to address this in part by introducing a pilot for a Young Carers Card which is now operational in five Health Boards.

⁴⁷ <u>http://www.legislation.gov.uk/asp/2013/1/contents/enacted</u>

⁴⁸ Section 12A(1)(b)(ii) of the Social Work (Scotland) Act 1968 and section 23(4) of the Children (Scotland) Act 1995

- **15)** The principles set out in the SDS Act apply to young carers in their role as providers of services. The existing provisions about taking account of the views of carers in the assessment of the cared-for person also apply to young carers.
- 16) We propose that carers' legislation includes a principle about young carer involvement in care planning for service users (subject to consent) and support for themselves.
- 17) We want to take views with regard to young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers. We also see every reason for young carers to be involved in projects, institutions and services which make the most of their experiences. One such organisation is the Scottish Youth Parliament where there is young carer representation.

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 14: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

Question 15: Should we make provision for the involvement of carers" organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?

Question 16: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?

Question 17: What are your views on making provision for young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers?

Chapter 7

Planning and Delivery

- a) Carers Strategies
- b) Diversity and Equality in Provision

Summary

This chapter sets out proposals for statutory provision for the development and publication of local carers' strategies which will, amongst other things, address issues of need and demand for support. There is also a proposal in respect of developing the market in support services for carers and young carers so that support is available to meet need.

Carers strategies

- Under the Public Bodies (Joint Working) (Scotland) Bill there is a requirement for integration authorities to prepare strategic plans which will set out arrangements for delivery of integration functions and how the national health and wellbeing outcomes will be met.
- 2) The provisions in the Children and Young People (Scotland) Bill for the preparation of children's services plans will support carers of disabled children indirectly and young carers. In preparing such plans local authorities and health boards must give "other service providers" the opportunity to contribute to the plan. They must also consult organisations representing the relevant interests.
- 3) Presently, most if not all, local authority areas have local carers strategies. Some are prepared jointly with the Health Board. The local strategies provide the strategic framework for the development of services for carers. Some areas have local young carers strategies.
- 4) The strategic plans required under the integration of health and social care, the children services plans and the carers and young strategies should all work together for the benefit of service users and carers.
- 5) Because the integration strategic plans will be high-level, although they will reflect on the needs of carers, and because they will not all cover children"s services, we see a need to continue with local carers strategies.
- 6) Local carers strategies should address issues about need and demand for support for carers within a wider context of joint strategic commissioning. The Change Fund plans under Reshaping Care for Older People demonstrated progress in this area with regard to carers of older people.

- 7) Further progress can be made. In relation to short breaks, for example, the report produced by Reid-Howie Associates Ltd for Shared Care Scotland in 2010 (*It's About Time: An Overview of Short Break (Respite Care) Planning and Provision in Scotland*)⁴⁹ concluded that there is limited commitment to putting in place strategies to identify unmet need and that there is huge variance in decisions on priorities. We accept that matters have moved on in some areas since this report was produced.
- 8) In order to ensure a good focus by local authorities and Health Boards on strategic planning, we propose statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers' strategies which must be kept under review and updated every three years. This builds on the proposals in chapter 6 on carer involvement but with a focus here on carers" strategies. Furthermore, local carers strategies should address unmet need and demand for support to carers. The identification of latent or unmet need is valuable.
- 9) We do not propose statutory provision for the preparation of young carer strategies given the proposals in the Children and Young People (Scotland) Bill for preparation of a children's services plan. However, local areas can if they wish produce young carer strategies.

Diversity and Equality in Provision

- **10)** Updated guidance on joint strategic commissioning will include guidance on developing the market for services.
- 11) Section 19 of the Social Care Self-directed Support (Scotland) Act about the "promotion of options for self-directed support" provides for local authorities to promote, in so far as is reasonably practicable, a variety of providers of support in relation to supported persons.
- 12) There is currently no legal duty in social care law to provide support to carers. Therefore, it is understandable that there is an underdeveloped market of providers to support carers with counselling, advocacy, short breaks and other forms of support. It is necessary therefore to develop and support the market.
- 13) We see merit in legislative provision that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that sufficient support services are available for meeting the needs for support to carers and young carers in the area.

⁴⁹http://www.sharedcarescotland.org.uk/_nonhtdocs/pdfs/lts%20About%20Time%20Report%20Nov% 202010.pdf

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 18: Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers strategies which must be kept under review and updated every three years?

Question 19: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

Chapter 8

Identification

Summary

This chapter sets out issues about the identification of carers and young carers.

Its purpose is to seek views on the way forward to help support the identification of carers and young carers.

Introduction

- It is necessary to identify carers so that they can have access to a carer's assessment (Carer's Support Plan) (see chapter 2) and to support (see chapters 3 and 4). Young carers will have their assessment of wellbeing and support planning taken forward within the Getting it Right for Every Child (GIRFEC) approach and the statutory framework within the Children and Young People (Scotland) Bill.
- 2) Yet identification remains a challenge. Some people will not wish to be identified as carers at all whilst others will initially reject the idea of identification to then seek identification later on as the caring role intensifies. Identification of oneself as a carer can also depend on other factors such as the illness of the person being largely self-managed until the point of it becoming more serious.
- Carers and young carers can be identified by social work, health and other professionals in different ways, including:
 - when a patient is admitted to hospital;
 - when a patient is discharged from hospital;
 - at the GP surgery either for their own appointment or when they accompany the person they care for to the surgery;
 - when in contact with community health services;
 - at the pharmacy when they pick up prescriptions for the person they care for or for themselves;
 - when the person they care for is assessed by social work; and
 - through day-to-day interactions in a school, college or university setting.
- 4) There are various national policy initiatives to help support the identification of carers by professionals. These include the Scottish Government's funding of NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC) and the College Development Network for workforce development. The Royal College of General Practitioners Scotland's guidance on carer identification is available to GPs. The Scottish

Government has published an Admission, Transfer and Discharge Protocol for hospital patients, which has a role in carer identification.⁵⁰

- 5) There are local initiatives too. A few local authorities, for example, run public information campaigns aimed at people who provide unpaid care, and particularly those who are hidden and who are not accessing support.
- 6) NHS Boards have a role in carer identification as the first point of contact for many carers is with health centres, GP practices and in hospitals. A few Boards fund the voluntary sector to have a presence in some GP practices whilst another approach is to run awareness-raising sessions in libraries and other community facilities.

Carers Register

- 7) One of the ways to help ensure the identification of carers is through the requirement of GPs to hold a Register of Carers as this is included in the core element of the GP Contract and is therefore a contractual agreement.
- 8) In the GP clinical system a "read code" is applied to identify a carer, and a search can then be undertaken within the GP clinical system, which is effectively the Register.
- 9) The aim is to identify carers within the GP practice so that they can be referred on for a carer's assessment and potential support.
- 10) Some GP practices offer carers on the Register access to extended appointments, health checks and information on the flu vaccine. However, under the core contract there is no requirement for this to take place. Since carers are nonetheless entitled to the flu immunisation, we would expect GP practices to target carers. Carers may indeed need longer consultations at times as will be the case with others such as people with learning disabilities, mental health issues, multi-morbidity and people who are asylum seekers.
- 11) In order to facilitate further carer identification through active Registers of Carers held by GP practices, we have considered whether we should have a statutory requirement in relation to GPs to identify carers through use of the Register of Carers. We have, however, ruled this out.
- 12) Instead, we see merit in ensuring that good practice is widely shared amongst Health Boards. We know, for example, that one Health Board has NHS Carer Support Teams that raise awareness about carers in GP practices.

⁵⁰ <u>http://www.scotland.gov.uk/Topics/Health/Quality-Improvement-Performance/NHS-Performance-Targets/Delayed-Discharge/Protocol</u>)

Information Point

The majority of Lanarkshire GP practices now have a member of staff with Carer Liaison responsibilities who will help identify carers, encourage them to be entered on the GP Carers Register and signpost them to appropriate services and supports. During 2012-13 the Lanarkshire Carers Support Team made some 407 visits to GP practices across Lanarkshire and provided some 160 carer awareness raising sessions to 1,530 NHS and GP practice staff. The success of this work is reflected in the number of carers on the GP Carers Register, with 5,347 carers registered at 31 March 2013 (an increase of 6% from 2011-12) of which 59% were encouraged to access routine screening/monitoring appointments during 2011-12.

- **13)** We also see merit in asking Health Boards to monitor compliance with the core contractual elements and to confirm the outcome to the Scottish Government.
- 14) We have also considered whether local authorities should have a Carers Register – a few local authorities operate such a Register already. It makes sense for the local authority to work towards identifying carers at key points, for example, when the social worker is assessing needs of the cared-for person.
- 15) One of the issues with local authorities holding and publicising a Carers Register to be used proactively for carer identification is that it could lead to multiple Registers given the GP requirement to have a Register of Carers. This could lead to confusion and duplication of activity.
- 16) There would also need to be compliance with data protection legislation and ensuring that consent and confidentiality issues are robustly dealt with. Moreover, there would need to be a facility for other agencies and organisations such as Scotland"s colleges and universities to be able to add or remove names from the Register.
- 17) On balance, carer identification is an area where we have reservations about enshrining duties in law on local authorities or GPs as we are not convinced that more carers will be identified as a result of legislative provision. There is a need, however, to continue with further policy and practice developments.

Young Carers

18) The policy thrust must remain on the identification of young carers in schools (primary and secondary), colleges, universities, at the GP surgery and in hospitals.

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 20: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

Question 21: Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?

Question 22: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

Chapter 9

Carer and Cared-for Person(s) in Different Local Authority Areas

Summary

This chapter sets out issues about local authority responsibility for carrying out the Carer's Support Plan, providing support to carers and covering the cost of the support where the carer and cared-for person(s) live in different local authority areas. Its purpose is to seek views on the way forward.

The issues raised are unlikely to apply, at least to the same extent, where young carers are in a caring role.

Introduction

1) There is an issue about caring at a distance. Presently, under section 12AA(1) of the 1968 Act, an assessment is triggered by the carer asking a local authority to conduct it. A carer living in area "A" but caring for someone in area "B" might therefore choose to make that request to either area "A" or area "B." However, section 12AA(2)(a) says that a local authority is obliged to carry out the assessment if it appears to them that the person cared for is a person for whom they must or may provide community care services. So if the carer made his or her request for an assessment to area "A," that authority would not be under any obligation to carry out the assessment because it has no power or duty to provide community care services to the cared-for person in question. In such circumstances we would envisage that area "A" would signpost the carer to area "B", and it may also assist area "B" by carrying out the assessment on its behalf.

- 2) The practice on the ground varies. Presently, where carers are caring at a distance there can be some differences in practice (perhaps even between practitioners in any given authority) about which authority takes the lead in carrying out the carer's assessment. In practice, it might be more convenient for the carer to have the assessment in the area in which he or she lives.
- 3) There is also the question of which local authority would provide support to the carer where the carer lives in a different local authority area from the cared-for person. This does not appear to be a significant issue now since most authorities do not provide direct support to carers. However, where direct support is provided now, the current practice is likely to vary across the country.

The Future

4) The question about which authority should take the lead for undertaking the Carer's Support Plan and providing support is likely to become more of an issue in the future. Due to family migration patterns there are likely to be more carers living apart from cared-for persons in different parts of the country. Moreover, there is also likely to be an increase in the number of the Carer's Support Plans undertaken and more support provided directly to carers. There is also the issue of which authority will cover the costs of support provided directly to carers.

- 5) It is very likely that we will need certainty about which local authority is responsible for the Carer's Support Plan and the provision of support under carers' legislation. This is because, subject to the outcome of consultation, we plan to place a duty on local authorities to offer a Carer's Support Plan. It therefore seems necessary to have clarity about which local authority such a duty would fall on in any particular case.
- 6) Likewise, if we move from a power to support carers to a duty, then we might need to be clear about which authority that duty falls on. There will then be questions about which local authority bears the financial costs of the support, which does not necessarily need to be the same as the authority which decides to provide it.
- 7) We might expect that for practical reasons and for convenience that the Carer's Support Plan should be undertaken in the area in which the carer lives. In most cases, we might also expect that support such as advocacy, carer training or emotional support will be provided in the local authority area in which the carer lives. For the purposes of the Carer's Support Plan and for support, we might also expect that the lead local authority would collaborate with the other authority before finalising the Carer's Support Plan and the agreed support. This will be primarily due to the fact that any support to the cared-for person, which in turn supports the carer, will be provided by the local authority area in which the cared in which the cared-for person lives.
- 8) There is also the issue of which authority covers the cost of undertaking the Carer's Support Plan and providing support. There is an argument that where the authority in which the carer lives carries out the Carer's Support Plan and provides support, then the local authority area in which the cared-for person lives should reimburse the costs to the carer's local authority. This would apply too to the cost of a short break (where any costs are waived) as for any other type of support to the carer.
- 9) Section 86 of the 1968 Act allows area "A" to recover expenditure from area "B" if the person to whom they have provided listed forms of support is present in area "A", but actually ordinarily resident in area "B." Section 86 does not currently make any provision in relation to expenditure in respect of carers (whether direct expenditure in respect of services or direct payments to carers).
- 10) Where the carer cares for more than one person who each live in different local authority areas, then again, we might expect, for practical reasons, for the Carer's Support Plan to be undertaken in the area in which the carer lives. Likewise, any support to the carer is likely to be agreed by the carer's local

authority. It would however be difficult to split the cost of support amongst more than two authorities.

11) Since we are in new territory here, we would like to take views before reaching decisions on the way forward with regard to any legislative provisions or guidance.

Cross-border Situations

12) There are also similar issues when the carer or cared-for person lives in Scotland and the other family member lives in England, Wales, or Northern Ireland. We will explore these issues further.

WHAT DO WE WANT TO KNOW FROM YOU?

Consultation Questions:

Question 23: What are the views of respondents on which local authority should take the lead in undertaking the Carer's Support Plan, and agreeing support to the carer where the carer lives in a different local authority area to the cared-for person(s)?

Question 24: What are the views of respondents on which local authority should cover the costs of support to the carer in these circumstances?

Question 25: Should the Scottish Government with COSLA produce guidance for local authorities?

Definition of carer and young carer

Introduction

- 1) The main definition in law of a carer is "a person ("the carer") who provides, or intends to provide, a substantial amount of care on a regular basis for another person aged eighteen or over ("the person cared for") or for a disabled child." The carer can be a child so young carers are included in the definition. The definition is provided in law for eligibility for the carer's assessment.
- 2) There are other definitions too which are similar to the one above.⁵¹
- **3)** The definition used in *Caring Together*, and by local authorities and Health Boards in the same form, or adapted, is:

"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."

- 4) The definition in *Caring Together* cannot be used for the purposes of the carers "legislation. The definition needs to be shorter and sharper.
- 5) There will be some people who undertake caring, perhaps on a minimal basis, but who do not wish to be regarded as carers and who rule themselves out of eligibility for a Carer's Support Plan. This is discussed in chapter 2.

Adult carer

6) The term "carer" will mean an adult who provides or who intends to provide care for another adult who is an adult needing care or for a child needing care, except where the child needs care solely due to its age.

⁵¹ Paragraph 20 of schedule 12 to the Public Services Reform (Scotland) Act 2010 includes the definition: "someone who cares for (or "a person who cares for") a person, means someone who, being an individual, provides on a regular basis a substantial amount of care for that person, not having contracted to do so and not in the course of providing a care service." This definition is then referred to in section 12 of the Community Care and Health (Scotland) Act and in sections 14 and 16 of the Criminal Justice (Scotland) Act 2003.

Young carer

- 7) Where young carers are included in the provisions in the carers 'legislation, the definition will need to be changed to reflect this.
- 8) There are a few definitions of "young carer" in *Getting it Right for Young* Carers including two provided by young carers themselves. A third definition is from the Care 21 Report⁵² as follows:

A child or young person aged under 18 who has a significant role in looking after someone else who is experiencing illness or disability."

9) The fourth definition is Saul Becker's definition which has been adopted by The Blackwell Encyclopaedia of Social Work⁵³ as:

"children and young people under 18 who provide or intend to provide care, assistance or support to another family member. They carry out, often on a regular basis, significant or substantial caring tasks and assume a level of responsibility which would usually be associated with an adult ... The person receiving care is often a parent but can be a sibling or other relative who is disabled, has chronic illness, mental health problems or other condition connected with a need for care, support or supervision."

- Since none of the definitions can be used for law, the definition will be a 10) person under the age of 18 who provides or who intends to provide care for an adult or child needing care, except where the child needs care solely due to its age.
- 11) We have considered whether young carers caring for siblings should be within the scope of the proposed carers" legislation, especially if they are not the primary carer. However, the wellbeing of these young carers can be affected by the caring, especially in one-parent households. This does not mean that all siblings of disabled and/or ill children are young carers. Some are not.⁵⁴
- 12) Legislation allows for young carers to be eligible for support no matter whether they care for a disabled parent (or grandparent) or sibling or both. Providing that the local authority decides whether the young carer has needs in relation to the care which the young carer provides, or intends to provide, to the cared-for person, then the fact that the young carer might not be the main carer to a sibling or parent is irrelevant.

⁵² Care 21, The Future of Unpaid Care in Scotland, 2006 http://www.scotland.gov.uk/Publications/2006/02/28094157/1

⁵³http://saulbecker.co.uk/v1/downloads/young_carers/research%20policy%20and%20planning%20arti

cle%202000.pdf ⁵⁴ This does not go against section 23 of the Children (Scotland) Act where local authorities can provide services to, inter alia, children who are adversely affected by the disability of a family member but who are not young carers themselves.

13) Therefore, young carers who care for disabled and/or ill siblings as well as those who care for disabled and/or ill parents or others would come under the definition of young carer.

People who are not carers

14) As with current legislation, people will not be regarded as a carer if they provide or intend to provide care by virtue of a contract of employment or as voluntary work.

People who are employed by family members

- **15)** It is possible for a family member to be employed by another family member using a direct payment. This has been allowed for a number of years and local authorities will continue to have the discretion to agree to such arrangements under the new legal framework underpinning self-directed support.
- 16) The employment of a family member entails a formal employment arrangement. It relates to the provision of the state-funded support that would otherwise have been provided by the local authority. In some instances the employed person will not provide "unpaid care" in addition to their formal employment arrangement with their relative. However, in other instances the employed person may provide "unpaid" care in addition to the formal employment arrangement. In such instances, the carer may still have their own needs for support as a carer. In these circumstances, where the local authority considers that the relationship between the person needing care and the person providing care is such that it would be appropriate for the latter to be regarded as a carer, then the person will be regarded as such. Since there are no additional restrictions on the age of the employed personal assistant beyond those that are imposed by general employment legislation, then this would apply to young carers too.

Unpaid carer

17) Although the term "carer" can be confused with paid "care worker" in that paid care workers are sometimes called "carers," we do not propose to use the term in law of "unpaid carer." In fact, as set out in paragraph 15 above, the "carer" will sometimes be paid.

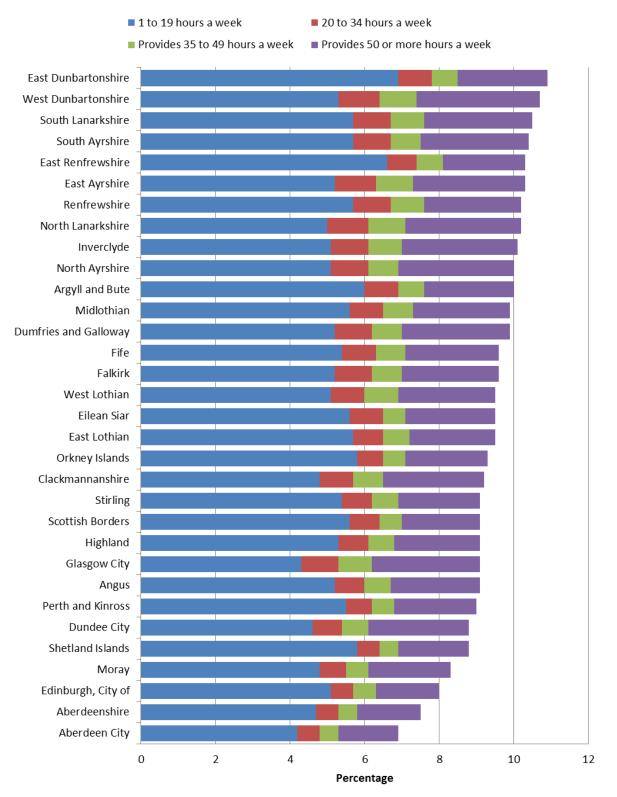
Provision of unpaid care by hours given by council area, Scotland, 2011

| All people | | 1 to 19 hours a week | 20 to 34 hours a week | Provides 35 to 49 hours a week | Provides 50 or more hours a week |
|--------------------------|-----------|----------------------------|--------------------------|--------------------------------------|----------------------------------------------|
| | | | | | |
| Scotland | 5,295,403 | 5.2 | 0.9 | 0.8 | 2.5 |
| Aberdeen City | 222,793 | 4.2 | 0.6 | 0.5 | 1.6 |
| Aberdeenshire | 252,973 | 4.7 | 0.6 | 0.5 | 1.7 |
| Angus | 115,978 | 5.2 | 0.8 | 0.7 | 2.4 |
| Argyll and Bute | 88,166 | 6.0 | 0.9 | 0.7 | 2.4 |
| Clackmannanshire | 51,442 | 4.8 | 0.9 | 0.8 | 2.7 |
| Dumfries and Galloway | 151,324 | 5.2 | 1.0 | 0.8 | 2.9 |
| Dundee City | 147,268 | 4.6 | 0.8 | 0.7 | 2.7 |
| East Ayrshire | 122,767 | 5.2 | 1.1 | 1.0 | 3.0 |
| East Dunbartonshire | 105,026 | 6.9 | 0.9 | 0.7 | 2.4 |
| East Lothian | 99,717 | 5.7 | 0.8 | 0.7 | 2.3 |
| East Renfrewshire | 90,574 | 6.6 | 0.8 | 0.7 | 2.2 |
| Edinburgh, City of | 476,626 | 5.1 | 0.6 | 0.6 | 1.7 |
| Eilean Siar | 27,684 | 5.6 | 0.9 | 0.6 | 2.4 |
| Falkirk | 155,990 | 5.2 | 1.0 | 0.8 | 2.6 |
| Fife | 365,198 | 5.4 | 0.9 | 0.8 | 2.5 |
| Glasgow City | 593,245 | 4.3 | 1.0 | 0.9 | 2.9 |
| Highland | 232,132 | 5.3 | 0.8 | 0.7 | 2.3 |
| Inverclyde | 81,485 | 5.1 | 1.0 | 0.9 | 3.1 |
| Midlothian | 83,187 | 5.6 | 0.9 | 0.8 | 2.6 |
| Moray | 93,295 | 4.8 | 0.7 | 0.6 | 2.2 |
| North Ayrshire | 138,146 | 5.1 | 1.0 | 0.8 | 3.1 |
| North Lanarkshire | 337,727 | 5.0 | 1.1 | 1.0 | 3.1 |
| Orkney Islands | 21,349 | 5.8 | 0.7 | 0.6 | 2.2 |
| Perth and Kinross | 146,652 | 5.5 | 0.7 | 0.6 | 2.2 |
| Renfrewshire | 174,908 | 5.7 | 1.0 | 0.9 | 2.6 |
| Scottish Borders | 113,870 | 5.6 | 0.8 | 0.6 | 2.1 |
| Shetland Islands | 23,167 | 5.8 | 0.6 | 0.5 | 1.9 |
| South Ayrshire | 112,799 | 5.7 | 1.0 | 0.8 | 2.9 |
| South Lanarkshire | 313,830 | 5.7 | 1.0 | 0.9 | 2.9 |
| Stirling | 90,247 | 5.4 | 0.8 | 0.7 | 2.2 |
| West | 90,720 | 5.3 | 1.1 | 1.0 | 3.3 |
| Dunbartonshire | | | | | |
| West Lothian | 175,118 | 5.1 | 0.9 | 0.9 | 2.6 |

Source: National Records of Scotland © Crown copyright 2013

Annex B (ii)

Provision of unpaid care by hours given by council area, Scotland, 2011



Summary of Manifesto Commitments and Scottish Government Actions to Support Carers and Young Carers

Manifesto Commitments 2011

Annual Carers Parliament: carers themselves are to have a more direct voice in the decision-making processes. The Carers Parliament will allow carers to raise the issues that impact most on their lives with MSPs and Scottish Government Ministers.

The Scottish Government has held two successful Carers Parliaments. The third will be held in October 2014. The First Minister announced at the second Carers Parliament the Scottish Government's intention to bring forward carers' legislation.

Employers Kitemark: we will create a new Caring for Carers Employers Kite-mark. This will recognise those employers who offer the best support to carers, allowing them the flexibility they often need to deliver care at home.

The Scottish Government is working with Carers Scotland and other organisations to deliver this commitment. A lot of preparatory and consultation work has been undertaken with employers" organisations, Chambers of Commerce, Trade Unions, carers and others. We are seeking to launch the scheme in a first phase this year.

Energy Assistance Package: we will extend the EAP to people on carer's allowance.

The necessary regulations to achieve this commitment are in force.

Short Breaks: we will continue to fund short breaks.

The Scottish Government is providing over £13 million for the voluntary sector Short Breaks Fund to 2015, and, subject to Parliamentary approval of the Budget, a further £3 million in 2015-16.

10,000 respite weeks: we will provide funding to maintain our commitment to an extra 10,000 weeks respite provision per year.

Taking into account changes in methodology of data collection, it is estimated that the number of respite weeks provided in Scotland has increased by 12,650 weeks (7.3%) in real terms between 2007-08 and 2012-13.

Carer Information Strategies: we will continue with £5 million investment each year in the CIS delivered through the NHS. This provides much needed support to local carer centres and training for carers.

The Scottish Government continues to invest in NHS Board Carer Information Strategies. The funding is providing a wide range of support for both carers and young carers across many different caring situations including dementia, mental health, learning disabilities, physical disabilities, substance misuse, palliative and end-of-life care etc. Subject to Parliamentary approval of the Budget, a further £5 million will be made available in 2015-16.

20% Change Fund: we want to see the Third Sector and carers play a key role as partners in the process given their important role in the lives of those cared for. To that end we will ensure that from 2012-13 onwards at least 20% of the Change Fund spend is dedicated to supporting carers to continue to care.

This means that at least £46 million will fund support to carers of older people up to 2015. We know from Change Fund plans that there has been a lot of progress across the country in supporting carers.

Carers as partners in the health service: we will work to make sure that unpaid carers are treated as partners in the health service, the treatment for those cared for can and will be improved when the knowledge and experience of their carers is fully taken into account.

Progress is being made in this area as evidenced in CIS and Change Fund plans. However, there is more to do to ensure that this commitment is fully carried through.

Education Maintenance Allowance: we will work to ensure the EMA takes account of the needs of young carers, with more flexibility to recognise the particular pressures that some youngsters face balancing school and caring responsibilities.

We have met with the Scottish Young Carers Services Alliance and others about this commitment. During the course of this year and beyond we will be putting in place a range of measures to ensure that schools, colleges and young carers themselves are fully aware of this commitment and that the specific needs of young carers are taken into account so that they receive their full entitlement to the EMA.

Young carers in schools: we will work to ensure that the particular circumstances of young carers are better recognised in our schools.

The Scottish Government has funded the Eryc and Trayc toolkit to help identify and support young carers in primary schools. The CIS funding is also work in schools. Through Additional Support for Learning legislation, young carers are being supported in schools. There is more to do to ensure a consistent approach across schools.

Therefore, all of the commitments have been met or are in progress.

Adult Carers

There are a wide range of policy developments underway in addition to those associated with the Manifesto commitments. We are working with SSSC, NES and other key stakeholders to deliver a range of activity that will support the health and social services workforce in their engagement with carers. Our aim is to support effective collaborative working so that carers as partners in care becomes a reality. A key component of this is raising awareness levels of the issues for carers across those workforces. We are working with the College Development Network so that those working in the FE sector are equipped to identify and support young carers and carers.

We fund a wide range of initiatives through programmes for the Third Sector including carer advocacy, carer training and Gypsy/Traveller programmes.

Young Carers

Young carers are supported through the wide range of initiatives for adult carers, including short breaks, workforce development, information and advice etc. Moreover, the Scottish Government has supported young carers through the annual Young Carers Festival, Opportunities for All employment initiative, action-based research with regard to BME young carers and the Young Carers Authorisation Card.

Carers Rights Charter

1) One of the recommendations of *Caring Together* is:

"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."

- 2) The Scottish Government commissioned Carers Scotland and the Minority Ethnic Carers of Older People Project (MECOPP) to work with partners to develop a Carers Rights Charter. The draft Charter is work-in-progress. It needs approval from COSLA Leaders as well as from the Association of Directors of Social Work (ADSW). The Charter is due to be published in the first half on 2014.
- 3) The Charter will set out in one place existing rights for carers. These rights are those that carers have both as citizens which are relevant to their caring role (for example, the right to request flexible working) and specifically as carers (for example, the right to a carer's assessment). To support the realisation of the rights the Charter will also set out what we are calling "expectations."
- 4) The purpose of the Charter will be both to inform carers of their rights and how they can expect them to be met and to improve the overall quality of the support and services carers receive.
- 5) The Charter will be updated on a regular basis to take account of future legislative developments which will confer rights on carers or which will have a beneficial impact on carers. These will include, subject to Parliamentary approval and Royal Assent, the Children and Young People (Scotland) Bill, the Public Bodies (Joint Working) (Scotland) Bill and the carers "legislation.
- 6) One of the main issues raised in the consultation to date on the draft Carers Rights Charter is the need for local authorities and other statutory and Third Sector bodies to sign up for the Charter. COSLA is clear too that there is a need to deliver the Charter. The Charter must be collectively endorsed through COSLA so that all authorities sign up for the rights and "expectations."

Young Carers

- 7) The Children and Young People (Scotland) Bill confers on Scottish Ministers the duty to keep under consideration whether there are any steps they could take which would secure better or further effect in Scotland of the United Nations Convention on the Rights of the Child (UNCRC) requirements. Scottish Ministers are also to promote public awareness and understanding of the rights of children.
- 8) *Getting it Right for Young Carers* did not contain a commitment to produce a Young Carers Rights Charter. However, the Scottish Government

subsequently agreed to commission in 2014 such a Charter from the Scottish Young Carers Services Alliance.

Annex E

Partial Equality Impact Assessment (EQIA)

Carers Legislation

January 2014

Carers Legislation – Partial Equality Impact Assessment

Introduction

- The public sector equality duty requires the Scottish Government to assess the impact of applying a proposed new or revised policy or practice. It is a legislative requirement. More importantly, however, at the end of most policies there are people. People are not all the same and policies should reflect that different people have different needs. Equality legislation covers the characteristics of: age, disability, gender reassignment, sex, pregnancy and maternity, gender including pregnancy and maternity, race, religion and belief, and sexual orientation.
- 2. An equality impact assessment (EQIA) aims to consider how a policy for example, activities, functions, strategies, programmes and services or processes, may impact, either positively or negatively, on different sectors of the population in different ways.
- 3. This partial EQIA lists some of the data that we have on the protected characteristics of carers, young carers and the people they care for. The responses to this consultation will help us to develop a full EQIA which will be published with the resulting Bill as it's introduced to Parliament.
- 4. In order to ascertain stakeholder views on the equality impact of the legislative proposals, a specific equality question is contained in the consultation"s Respondent Information Form. It is:

In relation to the Equality Impact Assessment, please tell us about any potential impacts, positive or negative; you feel the legislative proposals in this consultation document may have on particular groups of people.

Summary of demographics of carers

- 5. The following is an overview of existing data. This identifies some of the current evidence is available relating to particular population groups and population groups where there are gaps in evidence. The full EQIA will include, where available, further data and the likely impacts, both positive and negative, of the proposed legislation.
- 6. A large proportion of the data below is contained in the Scottish Government"s publication Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland.⁵⁵ The data contained within this document refers to the 2001 Census. It is expected that the full EQIA will reflect more data from the 2011 Census and other data that may emerge during this time.

⁵⁵ Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland - <u>http://www.scotland.gov.uk/Resource/Doc/319575/0102110.pdf</u>

- 7. This list is not definitive and, during the consultation period, more data may become apparent. Also, some of the data identified in this partial EQIA may turn out not to be relevant.
- 8. This list and links to other data have been produced to aid respondents to the consultation to consider the potential impact of its proposals on specific population groups.

| Population Groups | Demographics |
|-------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Age | • the Scottish Health Survey for 2007/2008 ⁵⁶ shows that most carers are from the middle to eldest age groups in society. The youngest in society (0-18 years) make up the smallest group of carers, accounting for 6% of all carers. |
| | the largest proportion of carers who look after someone who doesn"t live with them come from the 40-69 age groups. |
| | the number of respite weeks provided to Older Adults (65+) has increased from 85,270 in 2006/07 to 109,570 in 2010/11.⁵⁷ For adults aged 18-64 the number has risen from 55,770 in 2006/07 to 77,640 in 2010/11. And, for young people (0 to 17), this has risen from 22,610 in 2006/07 to 24,040 in 2010/11. the 65+ age group saw biggest increase in carers claiming the carers" allowance. The number of claimants increased from 4,730 in 2000 to 38,760 in 2008. |
| Disability | the 2001 Census data shows that around 12% of people who have a caring role report their own health as "not good". This increases to 18% of those carers providing over 20 hours of care per week. a recent study shows that many people providing over 35 hours of caring each week do not receive practical support and some stop work or retire early to care. In some cases, this is because the services for the cared-for person are not sufficiently flexible to allow the carer to continue in work.⁵⁸ |
| Sex | the 2001 Census data indicated that around 11% of women were undertaking a caring role, compared to 8% of men.⁵⁹ according to the 2001 census, 60% of carers in |

⁵⁶ Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland http://www.scotland.gov.uk/Resource/Doc/319575/0102110.pdf

Respite Care, Scotland 2011 - Official Publication -

http://www.scotland.gov.uk/Resource/Doc/360950/0122052.pdf

Carers UK (2013): The State of Caring (295 carers in Scottish sample)http://www.carersuk.org/professionals/resources/research-library/item/3090-the-state-of-caring-2013 Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland -

| | Scotland are female with 40% male. male carers are likely to provide less care the younger they are with over 80% of male carers aged 15 or younger providing less than 19 hours of care per week. They are most likely to be in extremely intensive caring roles (50+ hours per week) when they are aged 85+. female carers are likely to provide the least care when aged 16-34 and are most likely to provide extremely intensive caring (50+) hours when aged 15 or under. over 60,000 female carers were claiming the carers allowance in 2008, compared to 30,000 male carers. 63% of women, compared to 37% men provide care to someone not living with them. |
|------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| Sexual Orientation | • a publication released in 2007, sampling Edinburgh and the Lothians, by the LGBT Centre for Health and Wellbeing reported that 0.8% of respondents were in a full-time caring role. ⁶¹ |
| Gender Reassignment | no data exists is readily available, but will be explored as part of the full EQIA. |
| Race | the largest single BME group, according to the 2011, census, is the Pakistani community who make up 0.9% (49,000) of Scotland"s population (5,295,000). This is followed by the Chinese community with 0.6% (34,000) and then by the Indian community with 0.6% (33,000).⁶² The Gypsy/Traveller population account for 0.1% of the total population (4,000). 8.7% of the Pakistani population in Scotland provide some form of unpaid caring. 6.3% of the Chinese and 7.7% of the Indian communities provide some form of unpaid caring. Increasing evidence that Gypsy/Travellers experience significant health inequalities, high infant mortality rates, premature deaths and higher than average rates of major long-term conditions such as diabetes and |

http://www.scotlandscensus.gov.uk/documents/censusresults/release2a/StatsBulletin2A.pdf ⁶³ Informal Caring within Scotland's Black and Minority Ethnic Communities -http://www.mecopp.org.uk/files/documents/MECOPP%20publications/Informal%20Caring%20briefing

⁶⁰ Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland http://www.scotland.gov.uk/Resource/Doc/319575/0102110.pdf

⁶¹ LGBT Community Needs Assessment Report - <u>http://lgbthealth.org.uk/sites/default/files/Needs%20Assessment%20Sept%2007%20_Updated%20De</u> <u>c%2007</u>.<u>PDF</u>
 ⁶² 2011 Census: Key Results on Population, Ethnicity, Identity, Language, Religion, Health, Housing

and Accommodation in Scotland - Release 2A-

^{%20}sheet%203.pdf

| | cardiovascular disease. ⁶⁴ | |
|----------------------------|----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|--|
| Religion or Belief | no data exists is readily available, but will be explored as part of the full EQIA. | |
| Pregnancy and Maternity | no data exists is readily available, but will be explored as part of the full EQIA. | |
| Other – Deprivation | the biggest proportion of households with a carer (28%) are in the 20% most deprived data zones in the Scottish Index of Multiple Deprivation. The proportion of households with a carer then decreases steadily as deprivation decreases, so households in the 20% least deprived data zones in Scotland are also least likely to have carers (13%).⁶⁵ | |

Rationale and aims of policy

Purpose and intended effect

- 9. Carers, or unpaid carers as they are also known, are individuals who provide care to family members, partners, friends and neighbours of any age who are affected by physical or mental illness, disability, frailty or substance misuse. In many circumstances this will be in instances where the cared-for person has one or more conditions. This care provided by unpaid carers is estimated to save the health and social care services over £10 billion⁶⁶ every year in Scotland.
- 10. The Scottish Government is supporting unpaid carers and young carers through a range of policies under the Manifesto commitments of the Government and the national carers and young carers" strategies, *Caring Together* and *Getting it Right for Young Carers*. These policies are being supported with over £112 million of funding being directed into local authorities, Health Boards and the Third Sector to improve outcomes for unpaid carers, young carers and the people they care for.
- 11. However, despite these policies and investments the pace of improvement is not taking place quickly enough and unpaid carers and young carers across Scotland are experiencing differing levels of support. It is the aim of this carers' legislation to accelerate the pace of change in supporting carers and to bring a more consistent approach across all local authority and health board areas.

 ⁶⁵ Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland -<u>http://www.scotland.gov.uk/Resource/Doc/319575/0102110.pdf</u>
 ⁶⁶ Valuing Carers 2011 - Calculating the value of carers support -

 ⁶⁴Hidden Carers - Unheard Voices - Informal caring within the Gypsy/Traveller community in Scotland
 <u>http://www.scottish.parliament.uk/S4_EqualOpportunitiesCommittee/Inquiries/MECOPP.pdf</u>
 ⁶⁵ Caring in Scotland: Analysis of Existing Data Sources on Unpaid Carers in Scotland -

http://www.carersuk.org/media/k2/attachments/Valuing carers 2011 Carers UK.pdf

<u>Objective</u>

12. The objectives of the carers" legislation will be to:

- improve carers" health and wellbeing;
- sustain the caring role;
- enable carers to have life alongside caring;
- assist carers to remain in or return to work;
- enable access to community support networks; and
- prevent or delay hospital or residential carer admissions for cared-for persons.

How carers" legislation fits with Scottish Policy

- 13. The Scottish Government"s purpose is to focus Government and public services on creating a more successful country, with opportunities for all of Scotland to flourish, through increasing sustainable economic growth.
- 14. In order to achieve this purpose, Scottish Ministers are committed to the outcomes based approach as set out in the National Performance Framework's 10 year vision. This is a single framework to which all public services in Scotland are aligned, encouraging more effective partnership working. It is a framework based on delivering outcomes that improve the quality of life for people in Scotland, rather than on inputs and outputs. The National Performance Framework includes:
 - 5 Strategic Objectives describing where the Scottish Government will focus its actions;
 - 16 National Outcomes describing what the Scottish Government wants to achieve and the kind of Scotland we want to see.
- 15. The proposed carers" legislation closely aligns with the Healthier and Wealthier & Fairer Strategic Objectives, but also cuts across the Smarter objective.

16. It also aligns closely with a number of the National Outcomes, including:

- We live longer, healthier lives;
- We realise our full economic potential with more and better employment opportunities for our people;
- We are better educated, more skilled and more successful, renowned for our research and innovation;
- Our young people are successful learners, confident individuals, effective contributors and responsible citizens;
- We have tackled the significant inequalities in Scottish society;
- We have improved the life chances for children, young people and families at risk;
- We take pride in a strong, fair and inclusive national identity;
- Our people are able to maintain their independence as they get older and are able to access appropriate support when they need it;

• Our public services are high quality, continually improving, efficient and responsive to local people's needs.

Rationale for Government intervention

- 17. The Scottish Government, with partners, is making progress in supporting Scotland's carers and young carers. However, it is clear from research⁶⁷ and other resources that more can be done to improve support to carers and young carers.
- 18. The aforementioned policies, as well as other recent and forthcoming legislation, will benefit carers and young carers.
- 19. The Social Care (Self-directed Support) (Scotland) Act 2013 will provide a power for local authorities to support carers and young carers when it is planned to come into force on 1 April 2014. This will allow local authorities to support carers and young carers at their discretion.
- 20. The Children and Young People (Scotland) Bill, subject to Parliamentary approval and Royal Assent, will benefit both young carers and carers of disabled children by improving the way they are supported by services. It will promote cooperative working between services with the child at the centre.
- 21. The Public Bodies (Joint Working) Scotland Bill aims, through the integration of health and social care services, to improve outcomes for service users and carers by providing a framework to support improvement in quality and consistency across health and social care services.
- 22. Notwithstanding the aforementioned developments, there is a role for legislation specific to carers and young carers. The proposals contained within the consultation document cover the continuum of the caring journey. They aim to accelerate the progress that has already been made, ensure greater consistency and support for carers and young carers and help to achieve better and sustained outcomes. It also expected that carers" legislation will inspire renewed debate and ambition for what Scotland"s carers and young carers can expect.

Consultation

23. The legislation will be developed in a collaborative way involving colleagues from across and outwith the Scottish Government.

Within Government

24. We are working with colleagues across the Scottish Government to develop this legislation. This includes, but is not restricted to, the following teams:

⁶⁷ A body of research over the last few years commissioned by academia, research consultants and the national carers organisations.

- Children"s Rights and Wellbeing
- Integration and Reshaping Care
- Colleges and Adult Learning Funding and Policy
- Directorate for Legal Services
- Health Analytical Services
- Health Finance
- Higher Education and Learner Support
- Mental Health and Protection of Rights
- Office of the Chief Social Work Adviser
- Primary Care and Support
- Primary Medical Services
- Allied Health Professionals Unit
- Equalities Unit

Public Consultation

- 25. A formal consultation for the carers" legislation is scheduled to be held from January to April 2014 and will follow the standard 12 week consultation process.
- 26. We are planning to meet with a number of groups and organisations during this period, including but not restricted to:
 - Association of Directors of Social Work (ADSW)
 - Association of Directors of Education (ADES)
 - Convention of Scottish Local Authorities (COSLA)
 - Carers and Young Carers Strategy Implementation and Monitoring Group
 - Carers Reference Group
 - Health Boards
 - Local Authorities
 - National Carers Organisations
 - Scottish Council for Voluntary Organisations (SCVO)
 - Scottish Social Services Council (SSSC)
 - Scottish Youth Parliament
 - SOLACE

Formal Consultation

27. The formal consultation will take place between January and April 2014. The consultation materials will be available on the Scottish Government's website and will be sent to a wide range of stakeholders. We will also use social media, most likely twitter, to provide updates.

Current work to address the needs of carers from specific population groups

- 28. The Carers and Young Carers strategies, *Caring Together* and *Getting it Right for Young Carers*⁶⁸ acknowledge the impact of caring on specific population groups, including BME and LGBT populations. The *Getting it Right for Young Carers* strategy includes a specific action to develop, in partnership with the Scottish Young Carers Services Alliance, information, advice and support for LGBT Young Carers.
- 29. Following on from the Women's Employment Summit, held in September 2012, the Strategic Group on Women and Work was established, chaired by Angela Constance, Minister for Youth Employment, to provide strategic direction to the Scottish Government's work to improve women's position in the workplace, and provide updates to Parliament on progress. The Scottish Government''s Occupational Segregation Cross-Directorate Working Group has also been reconvened to address the specific recommendations on occupational segregation made at the Summit and those included in Royal Society of Edinburgh''s Tapping All Our Talents report. It reports directly to Ms Constance''s Strategic Group. Its membership includes the Scottish Government''s Carers Policy Branch ensuring that the issues surrounding unpaid carers, (60% of whom are female) accessing, or remaining in, employment are being considered.
- 30. The Minority Ethnic Carers of Older People Project (MECOPP) has produced a briefing on cultural competence.⁶⁹ This illustrates the importance of culturally competent approaches.
- 31. Short breaks for BME groups The voluntary sector short breaks fund has been supported with £13 million of funding from 2010 to 2015. The *Time to Live, Creative Breaks and Better Breaks* fund has supported 542 carers and 327 cared-for individuals from BME communities. They have also provided support to 123 projects that benefit BME carers and the people they care for.

Who needs to be consulted?

32. Through the consultation process a range of stakeholders will be consulted on the proposals for carers" legislation. These will include carers, young carers, cared-for individuals, local authorities, Health Boards, the Third Sector and relevant businesses. This consultation will include analysis of the impact on the population groupings detailed in the table on pages 3, 4 & 5 of this document.

⁶⁸ Caring Together : The Carers Strategy for Scotland 2010-2015 and Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015 http://www.scotland.gov.uk/Publications/2010/07/23153304/0

⁶⁹ An Introduction to Cultural Competence -

http://www.mecopp.org.uk/files/documents/MECOPP%20publications/Cultural%20competence%20bri efing%20sheet%206.pdf

Declaration and publication

I am satisfied with the partial equality impact assessment that has been undertaken and give my authorisation for the results of this assessment to be published on the Scottish Government"s website.

| Signed: |
|--------------------------------------------------------------------------------------|
| Date: 16 January 2014 |
| Michael Matheson, Minister for Public Health |
| Scottish Government Contact point: carersandyoungcarerspolicy@scotland.gsi.gov.uk |

Partial Business and Regulatory Impact Assessment

Title of Proposal

Carers and Young Carers Legislation

Purpose and intended effect

• Background

Carers, or unpaid carers as they are also known, are individuals who provide care to family members, partners, friends and neighbours of any age who are affected by physical or mental illness, disability, frailty or substance misuse. In many circumstances this will be in instances where the cared-for person has one or more conditions. This care provided by unpaid carers is estimated to save the health and social care services over $\pounds 10$ billion⁷⁰ every year in Scotland.

The Scottish Government is supporting unpaid carers and young carers through a range of policies under the Manifesto commitments of the Government and the national carers and young carers" strategies, *Caring Together* and *Getting it Right for Young Carers*. These policies are being supported with over £112 million of funding being directed into local authorities, Health Boards and the Third Sector to improve outcomes for unpaid carers, young carers and the people they care for.

However, despite these policies and investments the pace of improvement is not taking place quickly enough and unpaid carers and young carers across Scotland are experiencing differing levels of support. It is the aim of this carers' legislation to accelerate the pace of change in supporting carers and to bring a more consistent approach across all local authority and health board areas.

• Objective

- The objectives of the carers" legislation will be to:
 - improve carers" health and wellbeing;
 - o sustain the caring role;
 - enable carers to have life alongside caring;
 - o assist carers to remain in or return to work;
 - enable access to community support networks; and
 - prevent or delay hospital or residential carer admissions for cared-for persons.

⁷⁰ Valuing Carers 2011 - Calculating the value of carers "support http://www.carersuk.org/media/k2/attachments/Valuing_carers_2011____Carers_UK.pdf

How carers' legislation fits with Scottish Policy

The Scottish Government's purpose is to focus Government and public services on creating a more successful country, with opportunities for all of Scotland to flourish, through increasing sustainable economic growth.

In order to achieve this purpose, Scottish Ministers are committed to the outcomes based approach as set out in the National Performance Framework's 10 year vision. This is a single framework to which all public services in Scotland are aligned, encouraging more effective partnership working. It is a framework based on delivering outcomes that improve the quality of life for people in Scotland, rather than on inputs and outputs. The National Performance Framework includes:

- 5 Strategic Objectives describing where the Scottish Government will focus its actions;
- **16 National Outcomes** describing what the Scottish Government wants to achieve and the kind of Scotland we want to see.

The proposed carers" legislation closely aligns with the Healthier and Wealthier & Fairer Strategic Objectives, but also cuts across the Smarter objective.

It also aligns closely with a number of the National Outcomes, including:

- We live longer, healthier lives;
- We realise our full economic potential with more and better employment opportunities for our people;
- We are better educated, more skilled and more successful, renowned for our research and innovation;
- Our young people are successful learners, confident individuals, effective contributors and responsible citizens;
- We have tackled the significant inequalities in Scottish society;
- We have improved the life chances for children, young people and families at risk;
- We take pride in a strong, fair and inclusive national identity;
- Our people are able to maintain their independence as they get older and are able to access appropriate support when they need it;
- Our public services are high quality, continually improving, efficient and responsive to local people's needs.

Rationale for Government intervention

The Scottish Government, with partners, is making progress in supporting Scotland"s carers and young carers. However, it is clear from research⁷¹ and

⁷¹ A body of research over the last few years commissioned by academia, research consultants and the national carers organisations.

other resources that more can be done to improve support to carers and young carers.

The aforementioned policies, as well as other recent and forthcoming legislation, will benefit carers and young carers.

The Social Care (Self-directed Support) (Scotland) Act 2013 will provide a power for local authorities to support carers and young carers when it is planned to come into force on 1 April 2014. This will allow local authorities to support carers and young carers at their discretion.

The Children and Young People (Scotland) Bill, subject to Parliamentary approval and Royal Assent, will benefit both young carers and carers of disabled children by improving the way they are supported by services. It will promote cooperative working between services with the child at the centre.

The Public Bodies (Joint Working) Scotland Bill aims, through the integration of health and social care services, to improve outcomes for services users, including carers by providing a framework to support improvement in quality and consistency across health and social care services.

Notwithstanding the aforementioned developments, there is a role for legislation specific to carers and young carers. The proposals contained within the consultation document cover the continuum of the caring journey. They aim to accelerate the progress that has already been made, ensure greater consistency and support for carers and young carers and help to achieve better and sustained outcomes. It also expected that carers" legislation will inspire renewed debate and ambition for what Scotland"s carers and young carers can expect.

Consultation

The legislation will be developed in a collaborative way involving colleagues from across and outwith the Scottish Government.

• Within Government

We are working with colleagues across the Scottish Government to develop this legislation. This includes, but is not restricted to, the following teams:

- Children^s Rights and Wellbeing
- Integration and Reshaping Care
- Colleges and Adult Learning Funding and Policy
- Directorate for Legal Services
- Health Analytical Services
- Health Finance
- Higher Education and Learner Support
- Mental Health and Protection of Rights
- Office of the Chief Social Work Adviser

- Primary Care and Support
- Primary Medical Services
- Allied Health Professionals Unit
- Equalities Unit

• Public Consultation

A formal consultation for the carers" legislation is scheduled to be held from January to April 2014 and will follow the standard 12 week consultation process.

We are planning to meet with a number of groups and organisations during this period, including but not restricted to:

- Association of Directors of Social Work (ADSW)
- Association of Directors of Education (ADES)
- Convention of Scottish Local Authorities (COSLA)
- Carers and Young Carers Strategy Implementation Monitoring Group
- Carers Reference Group
- Health Boards
- Local Authorities
- National Carers Organisations
- Scottish Council for Voluntary Services
- Scottish Social Services Council (SSSC)
- Scottish Youth Parliament
- SOLACE

• Formal Consultation

The formal consultation will take place between January and April 2014. The consultation materials will be available on the Scottish Government's website and will be sent to a wide range of stakeholders. We will also use social media, most likely twitter, to provide updates.

Business

We will identify relevant organisations to meet with during the consultation period.

Options

Option 1 – Do Nothing

The first option would be to continue with the legislative situation as it currently is:

Carers Assessments

Section 12AA of the Social Work (Scotland) Act of 1968 states that: "A person ("the carer") who provides, or intends to provide, a substantial amount of care on a regular basis for a person aged eighteen or over ("the person cared for") may, whether or not the carer is a child, request a local authority to make an assessment ("the carer"s assessment") of the carer"s ability to provide or to continue to provide such care for that person. Specific Reference is made to carers of disabled children in the Children (Scotland) Act of 1995. It states that:

"...a person ("the carer") who provides, or intends to provide, a substantial amount of care on a regular basis for a disabled child may, whether or not the carer is a disable child, request a local authority to make an assessment ("the carer's assessment") of the carer's ability to provide or continue to provide such care for the child."

Information and Advice

There is statutory provision which requires local authorities to notify carers that they may be entitled to request a carer's assessment.⁷² With regard to Health Boards, Scottish Ministers may require Health Boards to prepare and submit to them a Carer Information Strategy for informing carers who appear to the Board to be entitled to a carer's assessment that they may have such rights.⁷³

There are also provisions in law requiring local authorities to provide service users with information⁷⁴ and also to publish information, for example, about relevant services they provide in respect of children.⁷⁵

The Patient Rights (Scotland) Act 2011⁷⁶ also contains provisions about providing information to patients and the provision of patient advice and support services.

The Social Care (Self-directed Support) (Scotland) Act 2013 includes duties for local authorities to provide information to adults, children, carers and young carers about self-directed support in relation to the four options available to service users and carers.⁷⁷

There are provisions in the Children and Young People (Scotland) Bill⁷⁸ for service providers to communicate information about the role of named persons and for service providers to share information.

Support

The Social Care (Self-directed Support) Scotland Act of 2013 will give local authorities, for the first time, a discretionary power to provide support directly to carers. It will also allow carers to choose one of the four option for self-directed support:

- Option 1 The making of a direct payment by the local authority to the supported person for the provision of support.
- Option 2 The selection of support by the supported person, the

⁷² Section 12AB of the Social Work (Scotland) Act 1968 and section 24A of the Children (Scotland) Act 1995

⁷³ Section 12 of the Community Care and Health (Scotland) Act 2002

⁷⁴ For example, section 12A(4)(b) of the 1968 Act

⁷⁵ Section 20 of the Children (Scotland) Act 1995

⁷⁶ <u>http://www.legislation.gov.uk/asp/2011/5/contents/enacted</u>

⁷⁷ Sections 9 and 10 of the Social Care (Self-directed Support) (Scotland) act 2013

http://www.scottish.parliament.uk/S4_Bills/Children%20and%20Young%20People%20(Scotland)%20 Bill/b27s4-introd.pdf

making of arrangements for the provision of it by the local authority on behalf of the supported person and, where it is provided by someone other than the local authority, the payment by the local authority of the relevant amount in respect of the cost of that provision.

- Option 3 The selection of support for the supported person by the local authority, the making of arrangements for the provision of it by the authority and, where it it's provided by someone other than authority, the payment by the authority of the relevant amount in respect of the cost of that provision.
- Option 4 The selection by the supported person of option 1,2 or 3 for each type of support, and where it is provided by someone other than the authority, the payment by the local authority of the relevant cost of the support.

Sectors and groups affected

The Public Sector

The public sector organisations that may be affected by the current situation include:

- Local Authorities
- Health Boards
- Care Inspectorate
- College Development Network
- Education Scotland
- Mental Welfare Commission for Scotland
- NHS 24
- NHS Education for Scotland
- NHS Health Scotland
- The Scottish Government
- Social Service Scotland Council
- Scottish Public Service Ombudsman
- Skills Development Scotland

The Private Sector

Information, Advice and Support for carers and young carers will be delivered mainly by Third Sector organisations. However, some services will be delivered by private organisations, especially in relation to issue of short breaks provision.

Third Sector

The Third Sector provides a high proportion of the services that support carers. There are a number of carers centres and young carers projects across the country that are given financial support to provide information, advice and support to carers and young carers. Carers" centres may also carry out a carer"s assessment on behalf of a local authority.

• Benefit of continuing with the current situation

The benefits of continuing with the current legal situation relate mostly to further progress which might be made through policy and practice developments. Moreover, the cost of implementing new legislation needs

to be taken into account. However, this does not take account of the expected longer term savings that will result of moving the provision of support away from crisis management towards prevention.

As part of the Bill process a full Financial Memorandum will be written. The financial implications of any new legislation will be fully developed in consultation with COSLA, local authorities, Health Boards and key Third Sector organisations.

Costs of continuing with the current situation

As highlighted, the cost of supporting carers will continue to be skewed towards the crisis management of caring situations at risk of collapse. In the majority of situations, crisis management care is delivered at a significantly higher cost than preventative and planned care approaches.

We recognise, however, that some preventative support is provided by carers centres, Health Boards, local authorities and Third Sector organisations. Moreover, the aim of the provisions in the SDS Act is to provide support on a preventative basis.

The proposed new legislation aims to move this focus towards the provision of preventative support with the aim of reducing the likelihood of caring relationships descending into crisis points. Moreover, the new legislation will provide an impetus for change, ensuring support to carers and young carers is provided on a more consistent basis.

Option 2 – Introduce Carers Legislation

The full consultation document covering the proposed legislative measures that will be developed is published in conjunction with this partial BRIA. These proposals aim to cover the continuum of unpaid caring:

- The Carer's Assessment (the Carer's Support Plan) The carer's assessment is the gateway to carers accessing support. The consultation will ask for views on changing the name of the carer's assessment to the "carer's support plan" to remove the negative connotations of the word assessment. It will also propose that the current "regular and substantial" test for carers" eligibility to be assessed is removed. It is also suggested that further criteria are removed from the assessment process. It is proposed that local authorities will be required to notify carers of the timescale for receiving an assessment and to be advised of the reasons if this timescale is not met.
- Information and Advice Access to relevant, accurate and timely information and advice is key to supporting carers, and the individuals they care for. Many carers say that this support, at an early stage and at appropriate milestones in their caring journey, is fundamental to maintaining their caring role. The consultation proposes that, to ensure information to carers is readily available, that a statutory duty is placed on local authorities to provide local information on carer's assessments

and available carer support. To reflect developments as the Public Bodies (Joint Working) (Scotland) Bill moves through the Parliamentary process, it is proposed that the statutory requirement for Health Boards to prepare and submit Carer Information Strategies is removed. This is due to the requirement becoming redundant as health and social care integration is established.

- Support to carers (other than information and advice) There are currently no provisions within social care law to directly support carers. Where local authorities support carers directly now, they are using the power to advance well-being in section 20 of the Local Government in Scotland Act 2003. From 1 April 2014, local authorities will have a discretionary power to support carers when the Social Care (Selfdirected Support) (Scotland) Act 2013 comes into force. The consultation proposes a range of scenarios relating to support. This includes:
 - retaining the status quo and using the forthcoming discretionary powers under the Self Directed Support Act;
 - introducing a duty for local authorities to provide support based on an eligibility framework by either direct support to the carer and/or by the provision of services to the cared-for person.

The consultation also asks respondents for their views on introducing a statutory duty for the provision of short breaks.

 Stages and Transitions - Carers experience difficulties and challenges as the individuals they care for move through both stages (e.g. the deteriorating health of the individuals they care for) and transitions (from children to adult services). Better planning around this would help to alleviate many of these issues.

Young carers may also experience difficulties as they move from being a young carer to becoming an adult carer. The consultation will look at whether there should be a legal obligation for local authorities to provide young carers with a carers support plan, if it appears that they will become an adult carer, ahead of their 18th birthday.

 Carer involvement – The consultation proposes to make provision for carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of health and social care integration. It also proposes to make provision for involvement by carers" organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration. The consultation suggests that carers" legislation includes a principle about carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation. It is also proposed that carers" legislation includes a principle about young carer involvement in care planning for service users (subject to consent) and support for themselves.

- Planning and Delivery The consultation proposes measures to ensure that carers and relevant organisations are involved in the planning of services with local authorities and Health Boards. It is proposed that they are involved in the creation of local carers" strategies and that those strategies are reviewed every three years. It is also proposed that local authorities with Health Boards take necessary steps to ensure the adequate provision of appropriate services to meet the needs of carers and young carers in their area.
- Identification Identifying carers and young carers is important to allow them to access a carer's assessment and support. The consultation proposes that no legislative measures are introduced in relation to the identification of carers and that improvements are continued through existing and forthcoming policies and initiatives, including the work of NHS Education Scotland (NES) and the Social Services Scotland Council (SSSC) around furthering the skills of the health and social care workforce on identification and support for carers and young carers.

Sectors or groups affected

The main sectors or groups affected by these legislative proposals are likely to be:

The public sector

The public sector organisations that will be impacted by the Bill will be the same as the list detailed under Option 1.

Private sector

The private sector organisations that will be impacted by the Bill will be the same as the list detailed under Option 1.

Third Sector

The proposals within the consultation document will cover a range of issues that will affect Third Sector organisations that provide support to carers and the individuals they care for.

Service Users

The proposed legislative measures being considered through the consultation process should have a positive impact on service users. By improving the support for their carers, who should be able to continue in their caring relationship, this will reduce and/or delay the likelihood of admission to hospital and residential care.

Carers

The proposed legislation will positively impact on carers. The proposals aim to improve outcomes for all carers and young carers by addressing the continuum of the caring journey.

| Benefits | | |
|----------------------------|---------------------|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| | • | By ensuring that carers are supported to continue in their caring roles, we can minimise the risk of their relationship with the individuals they care for deteriorating to crisis level. This has cost benefits as the cost of supporting carers at appropriate times, with a focus of prevention, during their caring journey will often be less than managing at crisis points. Costs versus benefits will be developed further as part of the Financial Memorandum accompanying a resultant Bill. |
| | • | The proposed legislation would set a minimum level of support that all carers in Scotland should expect to receive and will bring more transparency and consistency across local authority areas. |
| | • | The consultation"s proposal to remove the regular and substantial test for the carer"s assessment (carers support plan) will allow all individuals who carry out unpaid caring to be assessed for possible support. |
| • | | |
| Costs | • | A full consideration of costs will be carried out as we prepare the Financial Memorandum to accompany the resultant Bill. However, cost implications may include: |
| | | Costs to local authorities resulting from the requirement to provide information and advice. |
| | | Legislation to introduce a duty for carers to receive support would have financial implications for local authorities and possibly NHS Boards and the Third Sector. |
| | | • The possible removal of the regular and substantial test for carers receiving an assessment will likely lead to an increase in the overall number of assessments being carried out by local authorities or delegated third parties. However, the possibility of a gradient of assessment may reduce this number and/or the detail required for each assessment. |
| Scott | ish | Firms Impact Test |
| Throu stakel affecte | ghơ nolơ ed l | but the formal consultation period, the Bill Team will meet with a range of ders, including organisations, businesses and users who are likely to be by any proposed legislation. The outcome of these meetings will be and presented as part of the full BRIA. |
| - | <u>ر</u> | ompetition Assessment |
| · | Th au | the proposal that legislative measures are introduced that will see local thorities with Health Boards take steps, as far as is practically asonable, to ensure that sufficient support services are available for |

authorities with Health Boards take steps, as far as is practically reasonable, to ensure that sufficient support services are available for meeting the needs for support to carers and young carers in their area would have financial implications for local authorities and Health Boards. The consultation will indicate whether stakeholders feel that this will have an impact on competition within the current market.

• Test run of business forms

No new business forms will be brought in with the implementation of the proposed legislation.

Legal Aid Impact Test

As part of the Bill development process we will liaise with the Scottish Government Legal Systems Division to gauge whether any proposed legislation will affect Legal Aid. This will be detailed within the full BRIA.

Enforcement, sanctions and monitoring

The enforcement, sanctioning for non-compliance and monitoring of any proposed legislation will be detailed within the full BRIA.

Implementation and delivery plan

January – April 2014

- Launch of formal consultation.
- Publish of partial BRIA and EQIA with consultation document
- Series of events and meetings with relevant stakeholders, including businesses.

We currently aim to introduce the Bill to Parliament in 2015.

Post-implementation review

Any review process will be considered as the legislation is developed.

Summary and recommendation

The Scottish Government is committed to supporting carers in their roles and allowing them to continue to lead a life alongside their caring responsibilities. We want to ensure that carers are provided with adequate support, at the right time and that meets their own individual needs.

This cannot be achieved through one individual policy or initiative and legislation will play an important role in increasing the speed at which we bring about change in culture and services.

• Summary costs and benefits table This information will be detailed in the full BRIA and financial memorandum that accompanies the Bill.

Declaration and publication I have read the partial impact assessment and I am satisfied that, given the available evidence, it represents a reasonable view of the likely costs, benefits and impact of the leading options.

| Signed: |
|--------------------------------------------------------------------------------------|
| Date: 16 January 2014 |
| Michael Matheson, Minister for Public Health |
| Scottish Government Contact point: carersandyoungcarerspolicy@scotland.gsi.gov.uk |
| |

CONSULTATION QUESTIONS

The Carer's Assessment: Carer's Support Plan

Question 1: Should we change the name of the carer's assessment to the Carer's Support Plan?

🗇 Yes

🗌 No

Comments: Agree to change the name to Support Plan is more appropriate and in line with what carers themselves are saying and will reduce perceptions of stigmatisation

Question 2: Should we remove the substantial and regular test so that all carers will be eligible for the Carer's Support Plan?

🗌 Yes

🗌 No

Comments: Agreed-now sensible to remove the substantial and regular test

Question 3: Should we remove that part of the existing carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services/children^s services?

| ∑xYes | □ No | |
|-------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------|
| Comments: | Removal is supported | |
| | nould we introduce two routes through to the Carer's Support Plan – equest and by the local authority making an offer? | |
| ∐XYes | □ No | |
| Comments: F | Fully agree that this is a more commonsense approach | |
| Question 5: She provide care? | ould we remove from statute the wording about the carer's ability to | |
| ⊡ ves | □ No | |
| Comments: | Yes strongly agree that this will allow greater emphasis on outcomes | |
| length of time it | ould we introduce a duty for local authorities to inform the carer of the is likely to take to receive the Carer's Support Plan and if it exceeds advised of the reasons? | |
| 🙀 Yes | □ No | |
| Comments: | Yes in agreement with what is a well established commitment by pub | lic sector |
| Question 7: Ho and carers? | with communities w significant an issue is portability of assessment for service users | |
| Comments: | Particularly important for rural and remote communities | |
| | ould the Scottish Government and COSLA with relevant interests to take forward improvements to the portability of assessment? | |

🗌 Yes

🗌 No

Comments: Agreed

Information and Advice

Question 7: Should we introduce a duty for local authorities to establish and maintain a service for providing people with information and advice relating to the Carer's Support Plan and support for carers and young carers?

| 🙀 Yes | | 🗌 No | |
|-----------|--------|------|--|
| Comments: | Agreed | | |

Question 8: Should we repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer information Strategies to Scottish Ministers, subject to reassurances, which are subject in turn to Spending Review decisions, about the continuation of funding to Health Boards for support to carers and young carers?

| 🖌 Yes | □ No | |
|-----------|-----------------------------------------------------------|--|
| Comments: | yes time is right for this with shift towards Integration | |

Support to Carers (other than information and advice)

Question 9: Should we introduce a duty to support carers and young carers, linked to an eligibility framework?

| X Yes | | 🗌 No | |
|-----------|--------|------|--|
| Comments: | Agreed | | |

Question 10: Alternatively, should we retain the existing discretionary power to support carers and young carers?

| 🗌 Yes | □ _x No |
|-------------------|------------------------------------------------------------------|
| Comments: | |
| Question 11: Shou | Id we introduce a duty to provide short breaks? |
| 🗌 Yes | □ No |
| Comments: | Short breaks in themselves should not be given a seperate status |

Stages and Transitions

Question 12: Should we issue statutory guidance on the Carer's Support Plan which will include guidance for those undertaking the Carer's Support Plan on managing stages of caring? This would apply to adult carers only. (For young carers, practice guidance will be developed to support management of a Child's Plan through the stages of caring).

| ∐xYes | □ No |
|-----------|----------------------------------------------------------------------|
| Comments: | this would be beneficial for both the carer and the cared for person |

Question 13: Should new carers "legislation provide for young carers to have a Carer's Support Plan if they seem likely to become an adult carer? Any agreed support recorded in the Carer's Support Plan would be put in place after the young carer becomes a (young) adult carer.

| Ľ |] _x Yes | □ No |
|---|--------------------|---------------------------------|
| | Comments: | Sensible approach being adopted |

Carer Involvement

Question 14: Should there be carer involvement in the planning, shaping and delivery of services for the people they care for and support for carers in areas outwith the scope of integration?

Yes 🗌 No

Comments: Fully in agreement- carer experience and insights and knowledge should be central to service design

Question 15: Should we make provision for the involvement of carers" organisations in the planning, shaping and delivery of services and support falling outwith the scope of integration?

| Yes | □ No | |
|-----------|------|--|
| Comments: | | |

Question 16: Should we establish a principle about carer and young carer involvement in care planning for service users (subject to consent) and support for themselves in areas not covered in existing legislation?

| □ _X Yes | □ No |
|---------------------------|------|
| Comments: | |

Question 17: What are your views on making provision for young carer involvement in the planning, shaping and delivery of services for cared-for people and support for young carers?

Comments: Need to find more imaginative and well resourced methods for realising this

Planning and Delivery

Question 18: Should we introduce statutory provision to the effect that a local authority and each relevant Health Board must collaborate and involve relevant organisations and carers in the development of local carers strategies which must be kept under review and updated every three years?

🛛 X Yes

🗌 No

Comments: Integration timeline needs to be recognised and agree thatevery 3 years is appropriate

Question 19: Should we introduce statutory provision to the effect that local authorities with Health Boards must take steps to ensure, in so far as is reasonably practicable, that a sufficient range of services is available for meeting the needs for support to carers and young carers in the area?

| 🗌 Yes | □ _x No |
|-------|-------------------|
| | |

| Comments: | Concerned that this broad brush approach may not recognise the reality of |
|-----------|---------------------------------------------------------------------------|
| | rural areas- choice is a function of plenty |

Identification

Question 20: Should there be no legislative provision for GPs or local authorities to maintain a Carers Register in order to support the identification of carers?

🗌 Yes

🛛 No

Comments: We needd to look again at how this is best achieved on a voluntary basis

esp through GPs and broader community services Question 21: Should the Scottish Government ensure that good practice is widely spread amongst Health Boards about the proactive use of Registers of Carers within GP practices?

🛛 Yes

🗌 No

Comments: yes see above

Question 22: Should the Scottish Government ask Health Boards to monitor compliance with the core contractual elements of the GP contract?

∏xYes

🗌 No

Comments: Would carers register be a core element of this

Carer and Cared-for Person(s) in Different Local Authority Areas

Question 23: What are the views of respondents on the lead local authority for undertaking the Carer's Support Plan and agreeing support to the carer where the carer lives in a different local authority area to the cared-for person(s)?

Comments: Should be driven by area of residence of the cared for person .Need to ensure

Question 24: What are the views of respondents on which local authority should cover the costs of support to the carer in these circumstances? guidance is simplified and does not push

Comments: Again keep simple- area of residence of the care for person us into areas of dispute

Question 25: Should the Scottish Government with COSLA produce guidance for local authorities?

∐_kYes

🗌 No

Comments:

How to Respond

Carers Branch welcomes responses to this consultation paper by **16 April 2014.** Please send your response with the completed Respondent Information Form to: <u>CarersandYoungCarersPolicy@scotland.gsi.gov.uk</u>

Or to:

Carers Branch(Consultation) Adult Care and Support Division Directorate for Chief Nursing Officer, Patients, Public and Health Professions Director-General Health and Social Care The Scottish Government 2ER, St Andrew's House Edinburgh EH1 3DG

We would be grateful if you would use the consultation questionnaire provided in the consultation document or clearly indicate in your response which questions or parts of the consultation paper you are responding to as this will aid our analysis of the responses received.

This consultation, and all other Scottish Government consultation exercises, can be viewed online on the consultation web pages of the Scottish Government website at http://www.scotland.gov.uk/consultations.

The Scottish Government now has an email alert system for consultations SEconsult:

http://www.scotland.gov.uk/consultations/seconsult.aspx. This system allows stakeholder individuals and organisations to register and receive a weekly email containing details of all new consultations (including web links). SEconsult complements, but in no way replaces, SG distribution lists, and is designed to allow stakeholders to keep up to date with all SG consultation activity, and therefore be alerted at the earliest opportunity to those of most interest. We would encourage you to register.

Handling your response

We need to know how you wish your response to be handled and, in particular, whether you are happy for your response to be made public. Please complete and return the **Respondent Information Form** which forms part of the separate consultation questionnaire as this will ensure that we treat your response appropriately. If you ask for your response not to be published we will regard it as confidential and treat accordingly. All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore has to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

Next steps in the process

If you tell us we can make your response public, we will put it in the Scottish Government Library and on the Scottish Government consultation web pages. We will check all responses where agreement to publish has been given for any wording that might be harmful to others before putting them in the library or on the website. If you would like to see the responses please contact the Scottish Government Library on 0131 244 4565. Responses can be copied and sent to you, but a charge may be made for this service.

What happens next?

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us reach a decision on the proposed carers" legislation. We will issue a report on this consultation process in the Summer of 2014, which will be published on the Scottish Government"s website at: http://www.scotland.gov.uk/Publications/Recent

Comments and complaints

If you have any comments about how this consultation exercise has been conducted, please send them to:

Name: Kevin Fallon Address: Carers Branch Adult Care and Support Division The Scottish Government 2ER, St Andrew[®]s House Edinburgh EH1 3DG Email: <u>kevin.fallon@scotland.gsi.gov.uk</u>



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