

# **CARERS (SCOTLAND) BILL**

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## **POLICY MEMORANDUM**

### **INTRODUCTION**

1. This document relates to the Carers (Scotland) Bill (“the Bill”) introduced in the Scottish Parliament on 9 March 2015. It has been prepared by the Scottish Government to satisfy Rule 9.3.3 of the Parliament’s Standing Orders. The contents are entirely the responsibility of the Scottish Government and have not been endorsed by the Parliament. Explanatory Notes and other accompanying documents are published separately as SP Bill 61–EN.

### **POLICY OBJECTIVES OF THE BILL**

2. It is the intention of the Scottish Government that Scotland’s estimated 745,000 adult carers and 44,000 young carers<sup>1 2</sup> should be better supported on a more consistent basis so that they can continue to care, if they so wish, in good health and to have a life alongside caring. In relation to young carers, the intention is similar to that for adult carers but that young carers should have a childhood similar to their non-carer peers. The objective of the Bill is to make real this ambition by furthering the rights of both adult and young carers.

3. The Scottish Ministers view the Bill as an important opportunity to extend and enhance the rights of both adult and young carers<sup>3</sup> in Scotland. This means empowering carers themselves to exercise their rights. It also means enabling professionals to make this happen. In relation to young carers, this complements the provisions in the Children and Young People (Scotland) Act 2014 (“the CYP Act”) requiring the Scottish Ministers to promote public awareness and understanding of the rights of children and young people.

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<sup>1</sup> Scottish Health Survey (SHeS). The number of carers identified through the SHeS is much higher than the number identified through the Census 2011. That figure stands at 492,231 adult carers and young carers combined. We believe that the difference is due primarily to the SHeS being an interview survey where each adult answers the question separately, rather than one person answering for the whole household: this more readily helps people to identify themselves as carers. The question is: “*Do you look after, or give any regular help or support to family members, friends, neighbours, or others because of either a long-term physical condition, mental ill-health or disability; or problems related to old age?*”

<sup>2</sup> A forthcoming Scottish Government publication will include data for carers in different age categories. This data is presented on the basis of under 16s and over 16s as the weighting in the SHeS is designed for this age split. Since the Bill’s definition of young carer relates to under 18s mostly (see footnote 3), the figures presented here make an estimate, based on the data, for 16 and 17 year-olds. The forthcoming publication will also contain a slightly different figure for the total of young and adult carers.

<sup>3</sup> In the Bill “adult carer” means a carer who is at least 18 years old but who is not a young carer. “Young carer” means a carer who (a) is under 18 years old, or (b) has attained the age of 18 years while a pupil at a school, and has since attaining that age remained a pupil at that or another school. The term “carer” is also assigned a meaning in the Bill and is used as an umbrella term for both adult and young carers.

4. The Bill sets out the legislative provisions which, once implemented, will further support both adult and young carers in Scotland. For the purposes of this Policy Memorandum, the term “carers” is used to refer to both adult and young carers unless they are being discussed separately. Then the terms “adult carers” and “young carers” are used.
5. Specifically, the Bill does the following, amongst other things—
- replaces the current carer’s assessment with a new adult carer support plan (ACSP) and provides a young carer statement (YCS) for all young carers;
  - provides for the establishment of an information and advice service for carers in each local authority area which must include a short breaks services statement;
  - introduces a duty to support carers whose needs cannot be met by general services in the community (including the information and advice service). The carer’s needs must meet local eligibility criteria in order for the duty to apply;
  - requires local authorities, in determining which support to provide carers, to consider in particular whether the support should take the form of, or include, a break from caring;
  - requires local authorities to prepare local carer strategies for their areas; and
  - requires local authorities and health boards to involve carers in carer services meaning services provided by the local authority or health board to carers and cared-for persons.

## **BACKGROUND**

6. In addressing the 2<sup>nd</sup> annual Carers Parliament on 1 October 2013, the former First Minister, Alex Salmond MSP said in support of introducing legislation to further support carers—

“My assessment is that there are overwhelming grounds, socially, economically, morally, for seeking to build on the work that has been started and the work that has been done.”

7. The Bill proposal was subsequently included in *One Scotland: the Government’s Programme for Scotland 2014-15* published on 26 November 2014.<sup>4</sup> The First Minister, Nicola Sturgeon MSP said—

“In the coming year, we will extend support through a Carers Bill. The Bill won’t just give carers support – it will also give them a say. The Bill will ensure that they are involved in the planning and delivery of the services that affect them.”

8. Carers have always been an integral part of society, caring for family, friends and neighbours who are affected by physical or mental illness, disability, frailty or substance misuse. Most people are likely to have caring responsibilities at some stage in their lives, to know carers or to be cared-for persons. Sometimes there are mutual caring relationships where two people are both service user and carer for each other in an interchangeable way. The “turnover” in the

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<sup>4</sup> <http://www.scotland.gov.uk/Resource/0046/00464455.pdf>

carer population means that caring will touch the lives of most people. About three in five people will be carers at some point in their lives.<sup>5</sup>

9. Much progress has been made in recent years in raising awareness and understanding of the significant contribution that carers make to society and in their communities, the difference they make to the lives of those they care for but also the impact that caring itself can have on carers' own lives. Caring can be very rewarding but it can also limit carers' opportunities to pursue education, employment and leisure and recreational opportunities and to have fulfilling friendships and relationships i.e. to have a life alongside caring. Caring can limit young carers' participation in typical "growing up" activities enjoyed by young people.

### **Being a carer and public policy response**

10. Societal response to caring has changed significantly over time. Historically, people's general view was that caring, especially by adult carers, was something to be done stoically, dutifully, and without any State support. The idea of reaching breaking point due to the demands of caring was not accepted. This largely outdated view was replaced with society recognising and valuing carers for the work that they do but still without much being delivered in the way of practical support. The 1990s heralded a change in attitude leading to the publication in 1999 of *A National Strategy for Carers in Scotland*. This was followed in 2006 by the publication of the landmark report, *Care 21: The Future of Unpaid Care in Scotland*<sup>6</sup> informed by the voices of 4,000 carers. The Scottish Government and COSLA Carers Strategy for Scotland, *Caring Together* and *Getting it Right for Young Carers*<sup>7</sup> published in 2010 contained a wide range of actions for the Scottish Government, local authorities, health boards, the third sector and others. This Strategy is scheduled to come to an end in 2015. Consideration is being given to the way forward.

11. There is a myriad of different caring situations, each one unique to the people concerned whether it is caring at the beginning of life for a disabled or ill child or for an elderly relative at end of life or many situations in between. Public policy has been directed at improving the recognition of carers' needs and supporting carers within a "dual focus" that acknowledges that the caring takes place in a relationship. This recognises that the carer(s) and cared-for person(s) can have shared, intertwined and conflicting needs and that sometimes the cared-for person(s) can want, or need, more care than the carer is able or willing to provide to them. It also indicates that carers can benefit from support directed at them and the cared-for person.<sup>8</sup>

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<sup>5</sup> Carers UK (2001) *It Could Be You – A report on the chances of becoming a carer*

<sup>6</sup> *Care 21*. Available at: <http://lx.iriss.org.uk/sites/default/files/resources/0022797.pdf>

<sup>7</sup> *Caring Together* (2010). Available at: <http://www.gov.scot/Resource/Doc/319441/0102104.pdf>; and *Getting it Right for Young Carers* (2010). Available at: [http://www.carersuk.org/images/Downloads/Sco\\_YCStrategy.pdf](http://www.carersuk.org/images/Downloads/Sco_YCStrategy.pdf)

<sup>8</sup> Pickard, L.(2004) *The Effectiveness and Cost Effectiveness of Support and Services to Informal Carers of Older People*, London: Audit Commission and PSSRU, University of Kent, London School of Economics and University of Manchester. Available at: <http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/LitReview-Older-Effectiveness-final.pdf>; and

Rand, S. & Malley, J., (2014). Carers' quality of life and experiences of adult social care support in England. *Social Care in the Community*, 22(4), pp. 375-385.

## **The Carers Strategy and specific initiatives**

12. *Caring Together* and *Getting it Right for Young Carers* is the driving force nationally for ensuring further support to carers to help them achieve positive outcomes, goals and aspirations. The Scottish Government has, since 2007, invested £114 million in support to carers. As part of this investment, the Reshaping Care for Older People's Change Fund/carer component has helped to change the lives of carers of older people by the support provided to them. There are many examples of projects and programmes supporting key priority areas for carers. Three examples are provided below—

### ***Reshaping Care for Older People Change Fund***

#### ***a) Borders: Benefits and impact of the carer's assessment***

The funding has been used in the Borders to enable the carers centre to carry out more carer's assessments and to support carers. The Adult Quality of Life Index Questionnaire is used at two points in the carer's assessment pathway – once at the start of the process when the referral is first made and again following intervention. At the start, the majority of carers feel some level of stress, depression and exhaustion as a result of caring and more often the caring role affects the carer's life. Had they not had a carer's assessment at that point and continued as they were, it is likely they would have reached crisis and potentially ended up unable to carry on their caring role. This would have a knock-on effect to the cared-for person resulting in possible admission to hospital and/or residential care. Following the carer's assessment and appropriate onward referral or sign-posting, a second Questionnaire was sent out to the carer and responses showed that there was an improvement in how carers felt about their caring role.

#### ***b) Inverclyde: support at hospital discharge***

The Inverclyde Carers Hospital Discharge project – through the Change Fund, a carers' centre worker was seconded to work with the hospital discharge team at Inverclyde Royal Hospital raising awareness amongst staff of support for carers and providing support directly to carers.

#### ***c) Stirling: carer participation and involvement***

Older carers and carers of older people are made aware of and supported to access opportunities for further support. Carers are involved in the shaping of support services through engagement and regular consultation; active participation in the development of local strategies and action plans; reducing isolation, providing a better quality of life and maintaining carers' health and wellbeing.

13. The Voluntary Sector Short Breaks Fund<sup>9</sup> has supported, since 2010, over 32,000 carers and the Carer Information Strategy<sup>10</sup> funding of health boards has achieved significant progress

<sup>9</sup> This is managed on behalf of the Scottish Government by Shared Care Scotland and the Family Fund

<sup>10</sup> Under section 12 of the Community Care and Health (Scotland) Act 2002,

<http://www.legislation.gov.uk/asp/2002/5/section/12>, the Scottish Ministers may require any health board to prepare and submit to them a strategy (a "carer information strategy"). The Scottish Government issued guidance in 2003 on the preparation of the carer information strategy: [http://www.sehd.scot.nhs.uk/publications/cc2003\\_02full.pdf](http://www.sehd.scot.nhs.uk/publications/cc2003_02full.pdf). The Scottish Government has subsequently issued letters to health boards containing guidance on priorities for supporting carers. The Scottish Government allocates a total of £5 million per annum to health boards for the

with carer identification and support. The Equal Partners in Care (EPiC) initiative being taken forward by NHS Education for Scotland (NES) and the Scottish Social Services Council (SSSC)<sup>11</sup> is helping to ensure that health and social service workers are aware of carers and know how to work with them as equal partners.

### **Wider initiatives**

14. It is not just the national Carers Strategy and local carer strategies that are making a difference to the lives of carers. There are strategies, policy and practice developments at national and local level that are very relevant to improving outcomes for carers. The Scottish Government's strategies for dementia, autism, learning disabilities, mental health and others demonstrate determination to assure high quality care and support services that improve people's lives, including the lives of carers. The new Integrated Care Fund of £100 million<sup>12</sup> will be made available to health and social care partnerships in 2015-16 to support delivery of improved outcomes from health and social care integration, help drive the shift towards prevention and further strengthen the Government's approach to tackling inequalities.

15. Carers are also citizens. The Scottish Government can recognise and support carers by tackling health inequalities, ensuring a fair and prosperous and economically resilient country and by furthering participation in communities. To illustrate, with regard to young carers leaving school and young adult carers, then wider initiatives which benefit young people and young adults (for example, the Modern Apprenticeship programme) are as important as carer-specific support. The wider initiatives may, however, need some adjustment and tailoring to take into account the responsibilities of caring.

16. It is essential that carers are fully involved in decisions at local level about strategic planning decisions of concern and interest to them. A lot of progress has been made over the years in this regard with further developments under the Public Bodies (Joint Working) (Scotland) Act 2014<sup>13</sup> ("the Public Bodies Act") and implementing subordinate legislation which make provision requiring the involvement of carers and carers' organisations in relation to the planning, shaping and delivery of services and support which are provided in pursuance of "integration functions." This is consistent with the principles of co-production which underpin the Government's vision for person-centred public services which use the talents, capacities and potential of all of Scotland's people and communities in designing and delivering services and support to meet carers' needs.<sup>14</sup>

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pursuit of carer information strategies. This continues until 2015-16. Although the Scottish Government intends to repeal section 12 of the 2002 Act, funding could still be disbursed to health boards for support to carers as necessary.

<sup>11</sup> <http://www.sssc.uk.com/workforce-development/our-current-work/epic-carers-and-young-carers>

<sup>12</sup> Integrated Care Fund, Guidance for Local Partnerships: <http://www.scotland.gov.uk/Resource/0046/00460952.pdf>

<sup>13</sup> Census 2011

<sup>14</sup> Co-Production of Health and Wellbeing in Scotland  
[http://www.govint.org/fileadmin/user\\_upload/publications/Co-Production\\_of\\_Health\\_and\\_Wellbeing\\_in\\_Scotland.pdf](http://www.govint.org/fileadmin/user_upload/publications/Co-Production_of_Health_and_Wellbeing_in_Scotland.pdf)

## **Continuing challenges and concerns**

17. Much progress has been made and continues to be made through these and other initiatives. However, Scotland's carers continue to face challenges. It is clear from survey and research work that the intensity, duration and complexity of the caring situation have a profound influence over carers' health and wellbeing. The findings are set out below—

- while caring can be a positive and rewarding experience for both carers and cared-for persons, maintaining a balance between caring, family life and employment can be challenging and can have wider implications for the health and wellbeing of both the carer and cared-for person(s);
- poor carer health or distress can result in a greater use of health and care services by the cared-for person(s), especially older people through admission to hospital, referral to a day hospital or geriatric unit and admission to institutional care;<sup>15</sup>
- caring can have a negative impact on mental wellbeing, although there are considerable variations within carer groups. Some studies have shown that carers who provide a small amount of care have higher mental wellbeing scores than non-carers. For example, the Scottish Health Survey (SHeS) analysis of mental wellbeing amongst carers found that, after controlling for other factors, those who provide up to 4 hours of care each week had higher mean mental wellbeing scores than non-carers;
- however, the SHeS analysis showed that mental wellbeing scores decreased as hours of care provided increased. Carers who provide more than 35 hours of care each week were significantly more likely to exhibit signs of the presence of a possible psychiatric disorder than non-carers and other groups of carers. These results were generally stronger among women than men. These findings along with other research suggests that those most at risk of psychological distress are carers in more demanding care situations, providing more intensive care over an extended period;
- 70% of carers said they receive no support with their caring responsibilities, albeit that the SHeS includes a large number of adult carers (225,000 or 30%) who care for between one and four hours each week; 42% of carers who provide 35 hours or more of care say that they do not receive any support. The results of the Scottish Health and Care Experience Survey (HACE) are that 18% of adult carers indicated that they were not supported to continue caring whilst 38% were neutral on the subject;<sup>16</sup>
- carers providing significant but less intensive care are also at risk if they are not supported. This group of carers may receive little support from family, friends or services and at the same time may be juggling caring and employment. HACE showed

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<sup>15</sup> (1) Hirst, M. (2004) *Health Inequalities and Informal Care*, York: Social Policy Research Unit, University of York. Available at: <http://www.york.ac.uk/inst/spru/pubs/pdf/healthinequalities.pdf>

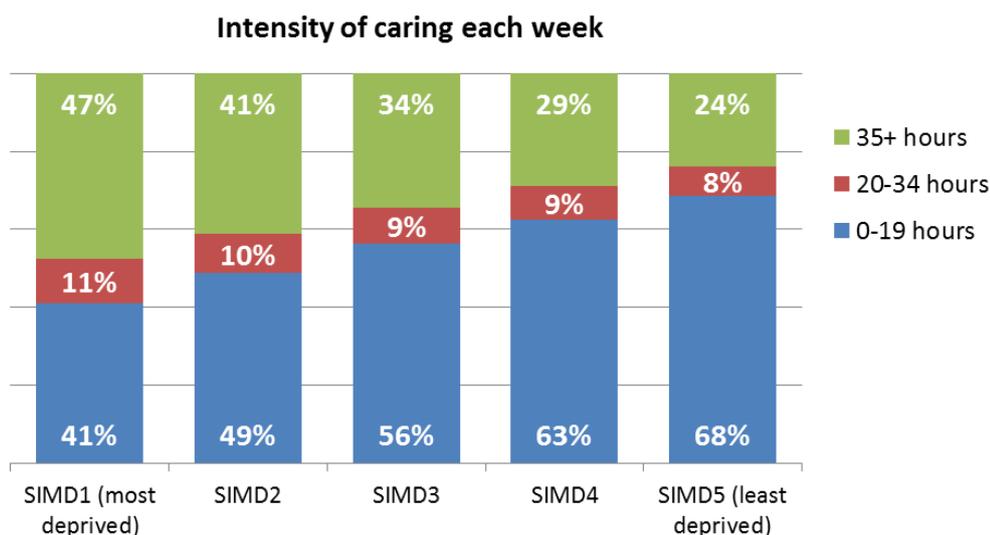
(2) The Princess Royal Trust for Carers and Crossroads Care (2011) *Supporting Carers: The Case for Change*. Available at: [http://www.carers.org/sites/default/files/supporting\\_carers\\_the\\_case\\_for\\_change.pdf](http://www.carers.org/sites/default/files/supporting_carers_the_case_for_change.pdf)

(3) Yeandle and Wigfiell (2011) *New Approaches to Supporting Carers' Health and Well-being: Evidence from the National Carers Strategy Demonstrator Sites*, Leeds: University of Leeds. Available at: <http://www.sociology.leeds.ac.uk/assets/files/research/circle/151111-6121-circle-newapproaches-complete-report-web.pdf>

<sup>16</sup> Scottish Government (2014) *Health and Care Experience Survey 2013-14* Available at: <http://www.gov.scot/Topics/Statistics/Browse/Health/GPPatientExperienceSurvey/Survey1314>

that these carers were less likely to indicate that they were supported to enable them to care compared with higher or lower intensity carer groups;

- young carers are much more likely to report they have a long-term mental health problem than non-carers;<sup>17</sup>
- 35% of adult carers caring for 35 hours a week or more are in employment.<sup>18</sup> Due to the impact of caring, 5% of adult carers have left employment, 6% have been unable to take up work and 7% have worked fewer hours;<sup>19</sup>
- caring brings financial stress with four in ten carers indicating that they had been in debt as a result of caring and five in ten feeling that financial worries were affecting their health;<sup>20</sup> and there are ‘hidden’ carers, including those from Black and Minority Ethnic (BME) and Gypsy/Traveller communities;<sup>21</sup> and
- 47% of carers in the most deprived areas care for 35 hours a week or more. This is almost double the level in the least deprived areas where 24% of carers care for 35 hours a week or more.<sup>22</sup> The chart below shows intensity of caring in each of the five Scottish Index of Multiple Deprivation (SIMD) categories.



18. The challenges also include the wider demographic context of an ageing population and more children with complex and exceptional needs being cared for at home. There is also the issue of an increased demand for carers. There is uncertainty over the future supply of unpaid

<sup>17</sup> Census 2011

<sup>18</sup> Census 2011

<sup>19</sup> Scottish Health Survey 2012-13

<sup>20</sup> *In Sickness and in Health*, Carers UK and other organisations (2012) - <http://www.carersuk.org/36-for-professionals/report/128-in-sickness-and-in-health>

<sup>21</sup> MECOPP (2012) *Hidden Carers, Unheard Voices*, , 2011-12, Edinburgh: MECOPP.

Available at: [http://www.mecopp.org.uk/resources-gypsy\\_traveller\\_resources.php?section\\_id=252](http://www.mecopp.org.uk/resources-gypsy_traveller_resources.php?section_id=252)

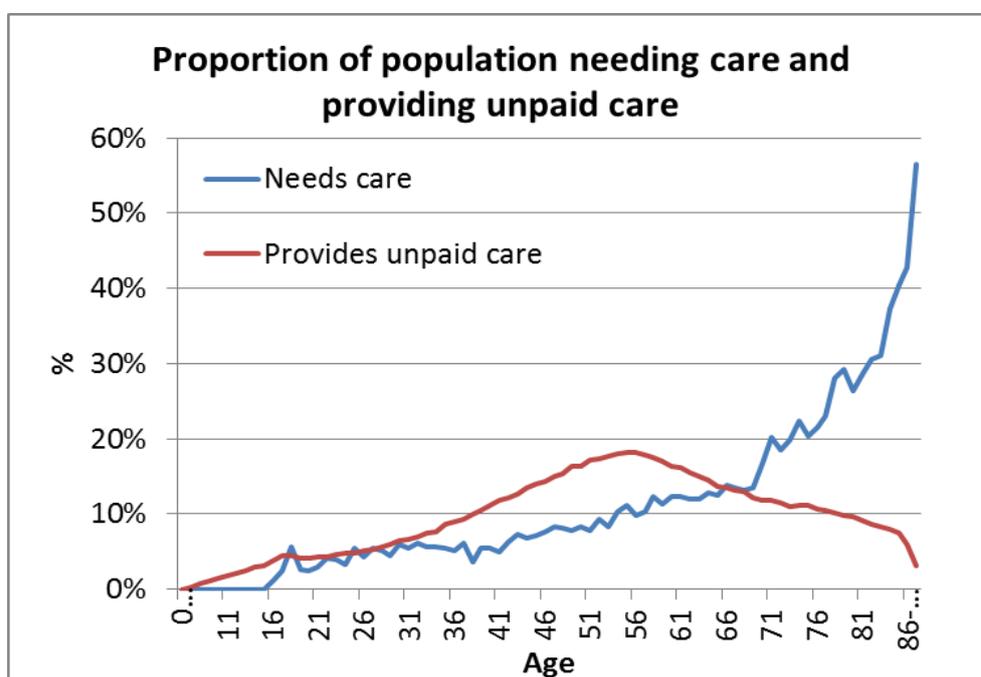
<sup>22</sup> Scottish Household Survey

care, with demand for unpaid care beginning to exceed supply by 2017 and the unpaid “care gap” growing rapidly from then onwards.<sup>23</sup>

19. To get an idea of the potential implications of demographic change for the need for, and availability of, carers, the Scottish Government has looked at the current age profile of both carers and cared-for people. This comparison is shown in the chart below. This should be interpreted as illustrative, as the data comes from two quite different sources with different definitions.

20. This shows that the age profile of carers is younger than that of cared-for people, as would be expected. What this implies is that demographic change – the disproportionate rise in the numbers of older people – will tend to increase the numbers of people of caring age (“the availability of carers”) more slowly than the numbers of people needing care. Using Census data the Scottish Government has made some simple projections using National Records of Scotland (NRS) population data (assuming that the proportion of the age cohort (by male and female) currently providing care or receiving care remains the same in the future). This confirms that “the availability of carers” increases at a much smaller rate than estimates of the future need for care. This implies that there will be greater pressure on those providing care.

**Proportion of the population needing care (paid and unpaid) and the proportion of the population providing unpaid care, by age<sup>24</sup>**



21. Family migration patterns too can have an impact on the supply of unpaid care especially in remote and rural areas. It is important therefore to respond to this unpaid ‘care gap’ by

<sup>23</sup> Pickard, L. (2015) A growing care gap? The supply of unpaid care for older people by their adult children in England to 2032, *Ageing and Society*, Vol. 35, 1.

<sup>24</sup> Source: NRS Census 2011 and Scottish Household Survey, various years. This is a ‘best guess’ comparison, given the differences in the data sources and definitions.

ensuring that carers are supported so that they do not drop out of the caring population and by finding new and innovative solutions to complement unpaid caring. These solutions include the use of telehealth and telecare being promoted by the Scottish Centre for Telehealth and Telecare<sup>25</sup> and by Carers Scotland.<sup>26</sup> Initiatives to develop the paid care workforce<sup>27</sup> are vital too.

## **ALTERNATIVE APPROACHES AND THE ROLE OF LEGISLATION**

22. The Scottish Government is pursuing a range of policy initiatives and approaches as part of its agenda to improve outcomes for carers. Some of these are set out in paragraphs 12 to 16 above. There are also Manifesto commitments in support of carers including two key commitments to ensure carer participation and involvement in the decision-making processes. These are the annual Carers Parliament<sup>28</sup> and the Young Carers Festival.<sup>29</sup>

23. The Manifesto commitment for a Caring for Carers Employers Kitemark to recognise and acknowledge those employers that support carers in the workforce is now being implemented across Scotland. The *Carer Positive* kitemark<sup>30</sup> is awarded to employers in Scotland who have a working environment where carers are valued and supported. *Carer Positive* employers recognise the importance of retaining experienced members of staff, reducing absence, and cutting down on avoidable recruitment costs.

24. The Scottish Government response to the Report on the Future Delivery of Public Services by the Commission chaired by Dr Campbell Christie<sup>31</sup> explains that its public sector reform programme for improving outcomes for the people of Scotland is based on a decisive shift towards prevention as well as on other important factors including the greater integration of public services at a local level, driven by better partnership, collaboration and effective local delivery.

25. Preventative approaches to supporting carers are vital in order to prevent or minimise escalating need with carers reaching crisis point before they are supported. It is incumbent on local authorities, health boards and the third sector to work on a preventative basis in order to achieve optimum results. One of the key messages from carers is to identify them early in order

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<sup>25</sup> <http://www.sctt.scot.nhs.uk/programmes/community/support-for-unpaid-carers/>

<sup>26</sup> <http://www.carersuk.org/scotland>

<sup>27</sup> <http://www.scotland.gov.uk/Topics/People/social-services-workforce>

<sup>28</sup> The Carers Parliament is an annual event which brings together both adult and young carers from across Scotland to debate key issues affecting carers and to raise issues with Scottish Government Ministers and MSPs. The next Carers Parliament will be held on 6 October 2015 in Edinburgh. The Scottish Government funds the Carers Parliament which is organised by Carers Scotland with the Scottish Government.

<sup>29</sup> The Young Carers Festival is an annual event which brings together over 600 young carers from across Scotland. The Festival provides a break from caring for the young carers, fun activities and opportunities to meet with, and influence, both national and local decision-makers. The Scottish Government funds the Young Carers Festival which is organised by the Scottish Young Carers Services Alliance which is part of the Carers Trust.

<sup>30</sup> <http://www.carerpositive.org/>

<sup>31</sup> *The Scottish Government's response to the Christie Commission, Renewing Scotland's Public Services – Priorities for reform in response to the Christie Commission*, September (2011)  
<http://www.gov.scot/Publications/2011/09/21104740/0>

to provide information and support before they reach crisis. Some carers have described only getting support once they were in crisis. One carer said as part of a survey for research:<sup>32</sup>

“I think they [carers] need an easier route to it, because if you’re really stressed, really hard work, it’s really hard to focus on how do I go about getting that, how would I get respite, oh I need to phone social work... it’s a hard route - when things are really very hard. And that’s when it comes to light, when you need it, it’s not when it’s good.”

26. Two alternatives to the Bill have been considered—

***Option 1: addressing carers’ needs through the Social Care (Self-directed Support) (Scotland) Act 2013,<sup>33</sup> (“the SDS Act”) the Public Bodies Act<sup>34</sup> and the CYP Act<sup>35</sup>***

27. The SDS Act, the Public Bodies Act and the CYP Act all support carers in different ways.

28. Under the SDS Act self-directed support allows people to choose how their support is provided, and gives them as much control as they want of their individual budget. SDS is the support a person purchases or arranges to meet agreed health and social care outcomes. SDS provides four options for getting support. Option 1 is a direct payment; under Option 2 the person directs the available support; under Option 3 the local authority arranges the support and Option 4 is a mix of the other options.

29. Its emphasis on choice and control and personalised solutions will support carers indirectly. When cared-for people have control over their health and social care and support, this helps to support carers.

30. The Public Bodies Act provides the framework which will support improvement of the quality and consistency of health and social care services through the integration of health and social care in Scotland. In driving integrated working between primary care (GPs, community nurses, allied health professionals etc) and secondary care (hospitals) and between health and social care, the Public Bodies Act will help to address people’s needs holistically and to ensure that resources follow patients’, service users’ and carers’ needs. The nine national health and wellbeing outcomes<sup>36</sup> set out in regulations are relevant to carers as members of the public. Outcome 6, that, “people who provide unpaid care are supported to look after their own health and wellbeing, including to reduce any negative impact of their caring role on their own health

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<sup>32</sup> IRISS, Shared Care & Coalition of Carers in Scotland (2012) *Rest assured? A study of unpaid carers’ experiences of short breaks*, Glasgow: IRISS. Available at: <http://www.iriss.org.uk/sites/default/files/iriss-rest-assured-full-report-2012.pdf>

<sup>33</sup> <http://www.legislation.gov.uk/asp/2013/1/contents/enacted>

<sup>34</sup> <http://www.legislation.gov.uk/asp/2014/9/contents/enacted>

<sup>35</sup> <http://www.legislation.gov.uk/asp/2014/8/contents/enacted>

<sup>36</sup> <http://www.scotland.gov.uk/Topics/Health/Policy/Adult-Health-SocialCare-Integration/Outcomes>

and well-being,” will require Integration Authorities<sup>37</sup> to support carers to help achieve this outcome.

31. The CYP Act will further the Scottish Government’s ambition for Scotland to be the best place to grow up in by putting children and young people at the heart of planning and services and ensuring their rights are respected across the public sector. The CYP Act, by improving the way services work to support children, young people and families, will support the carers of disabled children. Children and young people who are young carers will have a child’s plan where there is concern that their wellbeing will be adversely affected without a targeted intervention.

32. The acceleration of progress in the identification of carers, their needs and the provision of relevant support that is needed can be achieved by having a duty to support carers in the Bill (activated when a carer’s identified needs meet local eligibility criteria), rather than by relying solely on the discretionary power to support carers in the SDS Act. Whilst the three Acts each contain provisions which are necessary to support carers, the Bill will complement the three Acts, and will, in addition, provide a key platform in order to better support carers on a more consistent basis so that they can continue to care, if they so wish, in better health and to have a life alongside caring.

***Option 2: supporting carers through the provision of person-centred, joined-up, services in place for the cared-for person(s)***

33. Carers feel supported when the person they are caring for is supported themselves. Having the right services in place which improve the outcomes of the cared-for person(s) will be beneficial to the carer’s health and wellbeing. These services can include housing adaptations, care at home support, powered wheelchairs, effective medicine management and many more. Carers also often want to have good quality, up-to-date information about the condition of the person they are caring for.

34. The evidence<sup>38</sup> indicates that carers can be effectively supported through core services provided to the cared-for person. These impact through, for instance, reducing carer isolation by contact with care workers and providing assurance that the cared-for person’s needs are met and so contributing to the carer’s improved quality of life.

35. However, the evidence<sup>39</sup> also points to the benefits of direct support meeting the carer’s needs. Very often, a combination of support is required. There is also evidence that carers do not always recognise that they would benefit from support in their own right as their main focus

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<sup>37</sup> Depending on the type of integration scheme proposed (Public Bodies (Joint Working) (Scotland) Act 2014 S1.(4)(a)-(d) and subject to the Scottish Ministers’ approval, (s.9 (1) and(2) an integration authority can be a local authority, health board or as establish by the Scottish Ministers by order, an Integration Joint Board.

<sup>38</sup> Pickard, L.(2004) *The Effectiveness and Cost Effectiveness of Support and Services to Informal Carers of Older People*, London: Audit Commission and PSSRU, University of Kent, London School of Economics and University of Manchester. Available at: <http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/LitReview-Older-Effectiveness-final.pdf>

<sup>39</sup> Parker, G., Arksey, H. & Harden, M. (2010) *Meta-review of international evidence on interventions to support carers*, York: Social Policy Research Unit, University of York. Available at: <http://www.york.ac.uk/inst/spru/research/pdf/CarersLit.pdf>

of concern is the person they are caring for. Caring can impact on an individual's ability to look after their own health and wellbeing. Research<sup>40</sup> has found that women with intensive caring responsibilities are less likely to visit their GP than non-carers which indicates that they tend to prioritise the needs of the cared-for person over their own. Research<sup>41</sup> again highlights the benefits of a good quality carer's assessment which focuses on carers having time for themselves and the realisation of this through a personal-outcome based conversation.

36. The Bill will enable carers to be supported in their own right if their eligible needs meet the local eligibility criteria. They will, of course, continue to be able to be supported by services in place for the cared-for person(s).

### **Role of legislation**

37. There is no one policy or initiative that can bring about the kind of change required so that carers are supported in such a way that they can continue to care and to have a life alongside caring. There is therefore a fundamental role for legislation to accelerate and sustain the progress that has already been made, to bring about a step-change in the way that services support carers and to inspire renewed ambition about supporting carers.

38. Presently, under section 12AA of the Social Work (Scotland) Act 1968, carers who provide a substantial amount of care on a regular basis for persons aged eighteen or over may request a local authority to make an assessment of the carer's ability to provide or to continue to provide care for such persons. Section 24 of the Children (Scotland) Act 1995 ("the 1995 Act") makes similar provision in relation to the carers of disabled children. Scotland-wide, very few carer's assessments are carried out. In some areas less than 1% of the known carer population receive a carer's assessment. The research<sup>42</sup> on assessments quoted in Option 2 above found that sometimes the priority of practitioners is solely the cared-for person's assessment. The Bill replaces the carer's assessment with an adult carer support plan (ACSP) and young carer statement (YCS). The Bill will enable access by adult carers to the ACSP and by young carers to the YCS.

39. The Bill is founded on the preventative approach – access to the ACSP and YCS for all adult carers and young carers respectively without any prior testing around the threshold of caring on a substantial and regular basis. The ACSP and YCS will be light-touch as necessary so as not to discourage carers from having an ACSP or YCS as appropriate. By ensuring more effective delivery of support to carers, the Bill seeks to address the issues that may impede the wellbeing and positive outcomes for Scotland's carers.

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<sup>40</sup> Arskey, H., Hirst, M. (2005). *Unpaid Carers Access to and Use of Primary Care Services, Primary Health Care Research and Development* 6, pp.101-116. Available at: [https://pure.york.ac.uk/portal/en/publications/unpaid-carers-access-to-and-use-of-primary-care-services\(a53196fc-01f8-4626-8f47-efe086dc7968\)/export.html](https://pure.york.ac.uk/portal/en/publications/unpaid-carers-access-to-and-use-of-primary-care-services(a53196fc-01f8-4626-8f47-efe086dc7968)/export.html)

<sup>41</sup> Gamiz, R. & Tsegai, A. (2013) *Carer's Assessment and Outcome Focused Approaches to Working with Carers, A Joint Project Between Midlothian Council Community Care Team and VOCAL, Midlothian Carers Centre.* Scotland: IRISS/CRFR. Available at: <http://www.vocal.org.uk/assets/files/downloads/PROP%20Report%202013.pdf>

<sup>42</sup> *ibid*

40. The *Stitch in Time* research<sup>43</sup> on preventative approaches undertaken by Evaluation Support Scotland has a focus on third sector interventions that enable older people and carers to remain or be more socially connected. Loneliness and isolation are common problems amongst older people and carers and can have a severe detrimental effect on many aspects of health. The *Stitch in Time* work promotes the policy of older people and carers making connections and friendships in the community. Up-to-date information and signposting services, cafés, day and lunch clubs, activity and hobby groups and outings can all have a beneficial preventative impact. Local carers' organisations are good at facilitating these connections for carers (not only for carers of older people) as a form of preventative support to enhance carers' personal outcomes. The Bill will provide an additional impetus for this as it will make provision for the local authority to identify the carer's needs and once the carer's needs are identified, the local authority will consider which of those needs can be met through the provision of what is being termed "general services." These "general services" can include community-based supports. So through the Bill's provisions there will be a key focus on prevention, community capacity, empowerment and connectedness. Linking carers with community is one of the most important ways in which to improve their health and wellbeing.

41. As well as introducing the ACSP and YCS, the Bill, amongst other things, makes provision for a duty on local authorities to support adult and young carers whose identified needs cannot be met by the authority's general provision of the services, including the information and advice service established by the Bill. The carer's identified needs must then meet local eligibility criteria, which the local authority must set out, publish and review on a regular basis. In determining what support to provide to a carer, the local authority must consider, in particular, whether the support should take the form of, or include, a break from caring. There will also be a power to support carers whose needs are not eligible needs.

42. Each local authority must set the local eligibility criteria which are to apply within its area. A local authority must, when setting its local eligibility criteria, have regard among other things to such matters as the Scottish Ministers may by regulations specify. The Scottish Government will consult on these matters, but it is possible that they could include the desirability of taking a preventative approach to avoid carers' needs escalating to a more severe level.

43. The Bill's framework is designed to enable the best use of resources for supporting carers. If the duties and powers are used in the intended way then resources will not be polarised to either end of the eligibility criteria. The Scottish Government envisages resources being used to prevent the escalation of need and for the most acute support needs.

## **CONSULTATION**

44. The Scottish Government published, on 22 January 2014, its formal consultation for proposed legislation to support carers in Scotland.<sup>44</sup> The consultation was open for 12 weeks and closed on 16 April 2014.

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<sup>43</sup> <http://www.jitscotland.org.uk/resource/stitch-time-focus/>

<sup>44</sup> <http://www.gov.scot/Publications/2014/01/4757>

45. A total of 1,587 responses were submitted to the Scottish Government (1,422 of which were generated by surveys distributed by two stakeholder organisations). The remaining 165 responses were received using a standard response template. Responses are available on the Scottish Government website.<sup>45</sup> The 165 respondents can be broken down into the following groups—

<b>Respondent Group</b>	<b>Number</b>
<b>Individuals</b>	<b>32</b>
Carer/User Support	81
Local Authority	24
Health	13
Community Health and Care Partnerships (CHCPs)	5
Public Body	3
Professional Body	3
Representative Body	3
<b>Total Organisations</b>	<b>133</b>
<b>Total Responses</b>	<b>165</b>

46. The Scottish Government, in addition to the formal written consultation, ran and participated in a total of 16 consultation events attended by a wide range of stakeholders. These stakeholders included local government, health boards, carer organisations, other third sector organisations, carers, young carers and cared-for people.

47. It was essential that the views of young carers were represented in the consultation process, and to that end, an engagement event was commissioned with the Scottish Youth Parliament. This was held on a Saturday to facilitate young carer participation. Participants also included young adult carers over the age of 17.

### **Outcomes of consultation and engagement**

48. The independent analysis of consultation responses undertaken by *Why Research?*<sup>46</sup> and the Scottish Government's own consideration of the responses indicated that almost all stakeholders were broadly supportive of all or some of the Bill proposals. Others wanted the proposals to go further than those consulted on; for example, by introducing a duty on GPs and other health professionals to identify carers.

49. Feedback from the engagement events undertaken was similarly supportive and broadly positive about the Scottish Government's aspirations and the intentions behind the Bill's proposals. Carers and carers' organisations were supportive albeit seeking clarification of how the proposals would work in practice. They wanted to know about the resourcing of the Bill's provisions and how eligibility for support would work. The majority of local authorities which responded to the consultation were also broadly supportive, although some concerns were expressed about resourcing of the Bill, the proposed information and advice duty and any proposal for a duty to support carers.

<sup>45</sup> <http://www.gov.scot/Publications/2014/05/8784/0>

<sup>46</sup> <http://www.gov.scot/Publications/2015/03/7622>

50. The Scottish Government's response to the consultation was published on 4 March 2015. It can be found on the Scottish Government's website.<sup>47</sup>

51. In summary, the analysis of key consultation questions is provided below in relation to those who provided a view—

- a large majority supported the naming convention for the carer support plan thus removing the potentially stigmatising term, “assessment” and opening up its availability to a wider group of adult carers. Some wanted it to be available to young carers too. This issue is addressed in paragraphs 62-80 below;
- a majority of respondents supported the proposal to introduce a duty on local authorities to establish and maintain a service for providing carers in their areas with information and advice in relation to a range of matters pertaining to carers. This issue is addressed in paragraphs 108-113 below;
- a majority of respondents agreed with the proposal to repeal section 12 of the Community Care and Health (Scotland) Act 2002 about the submission of Carer Information Strategies to the Scottish Ministers. Some wanted reassurances about the continuation of funding to health boards for support to carers. This was because they saw the relatively modest investment of £5 million per annum resulting in a very good return on investment. The Financial Memorandum sets out the costs associated with the Bill's provisions including the cost of the information and advice service and the duty to support carers and states that the £5 million investment per annum should continue to help meet the costs;
- a majority of respondents supported the proposal to introduce a duty to support carers, linked to an eligibility framework. Comments were made and questions raised about the nature of the proposed framework and how it would operate. Further information is set out in paragraphs 89-94 below; and
- some respondents wanted the carer support plan to be available to young carers or for them to have their own young carer plan.

52. A large number of respondents supported the consultation proposal that a duty to support carers and young carers, linked to an eligibility framework should be introduced. On reflection, a duty to support carers in accordance with an “eligibility framework” would not work in practice. Instead, there will be a duty to support carers with eligible needs which are the carer's identified needs which meet local eligibility criteria.

53. The Scottish Government consulted on whether there should be a duty to provide short breaks. Some respondent groups supported such a duty. It was considered that whilst it is recognised that short breaks are an important source of support for many carers, they are one in a number of forms of support available to meet identified needs. It was considered appropriate therefore to place a duty on local authorities so that, in determining which support to provide to carers, they must consider in particular whether the support should take the form of a break from caring. The ACSP and the YCS also have to contain information about whether support should

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<sup>47</sup> *The Scottish Government Response to 'Carers Legislation – Consultation on Proposals – January 2014'* (2015). Available at: <http://www.gov.scot/Publications/2015/03/2211>

be provided in the form of a break from caring. The Financial Memorandum contains estimated costings for the duty to support carers, making provision for the cost of short breaks. Subject to Spending Review decisions, the Scottish Government also proposes to extend the duration of the voluntary sector short breaks fund beyond 2016.

## **POLICY OBJECTIVES: SPECIFIC PROVISIONS**

### **Key definitions**

#### *Current provision*

54. The main definition in law<sup>48</sup> 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 person cared for is a person for whom the local authority must or may provide, or secure the provision of, community care services.

#### *Consultation response*

55. The Scottish Government did not consult specifically on the definitions. However, most respondents supported the proposal not to include what is commonly termed “the regular and substantial test” in the definitions. Most respondents also supported removing that part of the carer assessment process whereby the cared-for person is a person for whom the local authority must or may provide community care services and children’s services.

#### *What the Bill does*

56. The Bill sets out definitions of “carer,” “young carer” and “adult carer.” Carers will no longer have to provide or intend to provide a substantial amount of care on a regular basis. Cared-for persons no longer have to be in receipt of community care services.

57. The Bill also sets out the meaning of “personal outcomes.” In relation to carers, personal outcomes include outcomes which would, if achieved, enable carers to provide or continue to provide care for cared-for persons. There is likely to be a focus on outcomes that are linked to maintaining and improving the health and wellbeing of the carer.

#### *Benefits of the Bill*

58. The benefits of the approach to the definitions at paragraph 56 are twofold. It will remove the need for local authorities to assess whether a carer is a “regular and substantial” carer, bringing with it a more consistent approach to eligibility for the ACSP and YCS across local authorities. There will also be a wider group of people who are cared-for persons.

59. Regulations made under the Bill may provide that kinship carers<sup>49</sup> who care for a disabled child (who might be the kinship carer’s grandson or granddaughter) and/or who care for

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<sup>48</sup> Section 12AA of the Social Work (Scotland) Act 1968 (“the 1968 Act”) and section 24 of the Children (Scotland) Act 1995 (“the 1995 Act”)

<sup>49</sup>Under the Looked After Children (Scotland) Regulations 2009, ‘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

their own son or daughter (who might have an issue with substance misuse) and/or who are carers in any other way would also be adult carers and come within the scope of the Bill's provisions on support.

60. The personal outcomes approach proposed in the Bill is enshrined in *Talking Points: Personal Outcomes Approach*.<sup>50</sup> The culmination of over six years of research, this practical guide brings together learning from practice, systems, culture and performance in one place, aimed both at organisations new to outcomes as well as those further down the road to becoming an outcomes focussed organisation. This guidance is clear that personal outcomes are identified through good conversations with people using services during assessment and support planning. It is also critical that the outcomes are reviewed, to ensure the continued relevance of support and services, and to support service planning, commissioning and improvement.

61. The Bill envisages that personal outcomes will be identified in the context of each carer's ACSP or YCS. The Scottish Ministers may set out in regulations the matters which are to be taken into account when identifying personal outcomes. For example, this might be matters which enable carers to provide, or continue to provide, care for cared-for persons. For carers to be able to provide or continue to provide care in this way, they will need a life alongside caring or to be able to participate in activities unrelated to the caring role.

### **Adult carer support plan (ACSP)**

#### *Current provision*

62. Under section 12A of the Social Work (Scotland) Act 1968,<sup>51</sup> carers of any age who provide, or intend to provide, a substantial amount of care on a regular basis may request a local authority to make an assessment ("the carer's assessment") of the carer's ability to provide or continue to provide care.<sup>52</sup>

#### *Consultation response*

63. Most respondents supported the proposal to have an ACSP for all identified adult carers if they wish to have the plan.

#### *What the Bill does*

64. The Bill sets out the duty on the responsible local authority (the local authority for the area in which the carer resides) to prepare the ACSP. The ACSP, which will be available to all adult carers, replaces the carer's assessment. The Bill contains provisions around the identification of personal outcomes, the content of the ACSP, the review of the ACSP and provision of information about the ACSP. All of the provisions combined will result in a plan

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relationship". 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.

<sup>50</sup>Cook, A. & Miller, E. (2012) *Talking Points: Personal Outcomes Approach, Practical Guide*, , Joint Improvement Team (JIT). Available at: <http://www.jitscotland.org.uk/wp-content/uploads/2014/01/Talking-Points-Practical-Guide-21-June-2012.pdf>

<sup>51</sup> The Social Work (Scotland) Act 1968<sup>51</sup>, S12A(1)(b)(i)

<sup>52</sup> Section 12AA of the 1968 Act and section 24 of the 1995 Act

which will enable the local authority, and indeed the adult carer, to have a comprehensive view of the adult carer's needs for support (if any) and how to meet those needs.

### *Benefits of the Bill*

65. The benefits of the ACSP are that it is a non-stigmatising plan unlike the present carer's assessment the name of which can act as a barrier to take-up by carers as it has negative connotations and can appear judgmental. The current wording in law concerning a carer's "ability" to provide care is replaced with the ACSP containing information about whether the carer is "able and willing" to provide care for the cared-for person. This is included so that there can be discussions about, for example, whether the carer is not able to provide care due to his or her own ill health. The emphasis on identifying the carer's personal outcomes is beneficial so that the engagement by the person preparing the ACSP with the carer during the ACSP process is characterised by a discussion on outcomes.

66. The ACSP is to contain information about the circumstances in which the plan is to be reviewed. Presently, not all carer's assessments are reviewed. The benefit of this new approach in law is that it will support a discussion during the preparation of the ACSP about the type of circumstance that would merit a review. Having a review process formalised in law will provide peace of mind for carers that their changed circumstances will be taken into account. Changed circumstances can mean that the caring situation is improved either because of the support that the carer is receiving or because the person they are caring for has improved health or both.

67. There may also be regulations about the circumstances in which plans are to be reviewed, the frequency of review and the procedure for review. The type of circumstance that could trigger a review would be the cared-for person being discharged from hospital.

68. Emergency, anticipatory or future planning is a concern for carers. This has a wide meaning and can cover, for example, planning for the care of the cared-for person for when the carer has passed away or planning for having alternative care arrangements in place to enable the carer to visit the GP. Planning of this nature will be covered in regulations about other information that an ACSP must contain.

## **Young carer statements**

### *Current provision*

69. As stated in paragraph 62 above, carers of any age who provide, or intend to provide, a substantial amount of care on a regular basis may request a local authority to make an assessment ("the carer's assessment") of the carer's ability to provide or continue to provide care. Therefore young carers, who are sometimes called child carers in policy and practice, come within the scope of this provision.

### *Consultation response*

70. Many respondents highlighted the experiences of young carers and young adult carers. A concern raised by some respondents was that young carers should have a specific young carer

plan or carer support plan in addition to, or instead of, the child's plan.<sup>53</sup> Others commented that the needs of young carers should sit within the GIRFEC (Getting it Right for Every Child)<sup>54</sup> approach.

#### *What the Bill does*

71. The Bill sets out the duty on the responsible authority<sup>55</sup> to prepare the YCS. Where a young carer attends an independent or grant-aided school, the school itself as "directing authority" will prepare the YCS. The local authority will, however, have a role in approving the YCS since some of the support could be provided or commissioned by the local authority. The health board will prepare the YCS for the estimated 200 pre-school children in Scotland who are young carers, but the emphasis here will be on stopping the caring role and supporting the parent or other cared-for person.

72. The YCS, which will be available to all young carers, replaces the carer's assessment. The Bill contains provisions around the identification of personal outcomes, the content of the YCS, the review of the YCS and provision of information about the YCS. The information in the YCS is to be made available to the young carer, others requested by the young carer and the named person.

73. The YCS will continue to have effect until the person who was previously a young carer but who is now an adult carer is provided with an ACSP. Any support that is provided to a young carer under a YCS which is also recorded in a child's plan because it constitutes a targeted intervention will continue to be provided under the YCS until such time as the YCS is replaced with an ACSP.

74. All of the provisions combined will result in a plan which will enable the responsible authority, and indeed the young carer, to have a comprehensive view of the young carer's needs for support (if any) and how to meet those needs.

#### *Benefits of the Bill*

75. The Scottish Government sees great merit in young carers having their own YCS. The benefits are that it will allow Scotland's young carers to discuss their personal outcomes and needs for support arising from their caring role with the person preparing the YCS. As set out in this Policy Memorandum, young carers are more likely to have mental ill health compared with other young people. The YCS process will be empowering and enabling for young carers.

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<sup>53</sup> The child's plan is provided under section 33 of the CYP Act 2014.

<sup>54</sup> GIRFEC is a consistent way for people to work with all children and young people. It's the bedrock for all children's services and can also be used by practitioners in adult services who work with parents or carers. The approach helps practitioners focus on what makes a positive difference for children and young people – and how they can act to deliver these improvements. Getting it right for every child is being threaded through all existing policy, practice, strategy and legislation affecting children, young people and their families. (Scottish Government website <http://www.gov.scot/Topics/People/Young-People/gettingitright/background>)

<sup>55</sup> The Bill will define "responsible authority". The Scottish Government proposal is that the authority which is responsible for preparing a YCS should be the same authority that provides the named person service under the CYP Act 2014 in respect of the young carer in question.

76. Many, but not all, young carers will have a wellbeing need which might be in relation to their caring role and/or other matters. The young carer will also require a child's plan under section 33 of the CYP Act 2014 if the wellbeing need can only be met, or met fully, by a targeted intervention. A targeted intervention is defined in section 33(4) of the CYP Act as a service which (a) is provided by a relevant authority<sup>56</sup> in pursuance of any of its functions, and (b) is directed at meeting the needs of children whose needs are not capable of being met, or met fully, by the services which are provided generally to children by the authority. For the purposes of supporting young carers, examples of targeted interventions include short breaks, training in moving and handling and medicine management and tailored information and advice.

77. The YCS scheme is to be designed in recognition of the fact that the extent of a young carer's caring role and responsibilities will vary both from young carer to young carer and also within individual cases, over the course of time as the nature of the caring role changes in relation to changes in a cared for person's need for care and/or changes to a young carer's own personal circumstances. With this in mind, it cannot be assumed that every young carer with caring responsibilities, will automatically have a wellbeing need, for it may be that the nature of the caring responsibility is such that the impact on a young carer's wellbeing is minimal or non-existent, such that there is little or no need for support. The absence of need for bespoke support, however, does not mean that the young carer is not entitled to a YCS. It is possible that such a young carer's need for support will, in time, intensify to such extent as to give rise to a wellbeing need which requires to be met through more formal support arrangements.

78. The Scottish Government understands that young carers might have concerns about the information being provided to the named person. The information will however be treated in confidence. The named person may also play a crucial role in the planning and delivery of support to the young carer, particularly, for example, where support to a young carer can be provided by the school. It is important that schools do play a role in delivering support such as allowing extra time for the completion of homework, allowing time off for the young carer if they are required at home and so on. The named person may also be preparing the child's plan where the young carer has wellbeing needs unrelated to caring.

79. The YCS will be similar to the ACSP. In addition, consideration will be given to the nature and extent of the care provided by the young carer being "appropriate". The benefit of this is that the young carer will have an opportunity to discuss issues such as if the level of care they are providing is appropriate to their age and circumstances.

80. The benefit of the continuation of a YCS until an adult carer is provided with an ACSP is that it should smooth the transition between young carer and adult services by ensuring there is no cessation of support when the young carer reaches 18. However, the young carer on becoming an adult carer can request an ACSP, especially if there is a change in their circumstances, for example, if he or she is pursuing further or higher education, taking up employment or moving away from home.

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<sup>56</sup> A "relevant authority" is defined in section 45 of the CYP Act as (a) health board, (b) local authority or (c) directing authority. "Directing authority" means (a) when used generally – (i) the managers of each grant-aided school, (ii) the proprietor of each independent school, (b) when used in relation to a particular establishment - (i) in relation to a grant-aided school, the managers of the school, (ii) in relation to an independent school, the proprietor of the school.

## **Provision of support to carers: eligibility criteria**

### *Current provision*

81. Under section 3 of the SDS Act, local authorities have a power to provide support to adult carers following an assessment completed under section 12AA of the 1968 Act (carer's assessment relating to carers of those aged 18 or over) and under section 24 of the 1995 Act (carer's assessment relating to carers of those under the age of 18).

82. Local authorities provide services to safeguard and promote the welfare of children in need under section 22 of the 1995 Act. This includes children who are in need (within the meaning of the 1995 Act) because they are young carers. Where a local authority provides services to children under section 22 of the 1995 Act then under section 8 of the SDS Act, the authority must provide the supported person with the opportunity to choose one of the four options for self-directed support. The supported person is the child (young carer) if aged 16 or over, or the child's parent or guardian in other cases.

83. The SDS Act does not make provision for eligibility criteria since it contains a power rather than a duty to support others.

### *Consultation response*

84. Many respondents commented that a duty to support both adult and young carers would bring clarity and transparency to the decision-making processes about supporting carers. Some respondents, both in support of and against the introduction of a duty, sought assurances about the funding of the duty. The Scottish Government consulted on a duty to support carers linked to an eligibility framework.

### *What the Bill does*

85. The Bill makes provision for local authorities to set local eligibility criteria. There is no eligibility framework as, in retrospect, this did not bring clarity to the context within which the duty to support carers is framed. The criteria will determine whether local authorities would be required to provide support to carers to meet carers' needs. So that there is full involvement of carers and carers' bodies in decisions about the criteria, the Bill requires local authorities to consult as appropriate with carers and carers' bodies. Local authorities will also be required to publish their eligibility criteria so that each authority can see the approaches taken by other authorities. There are also provisions for local authorities to review their eligibility criteria and to set revised criteria as necessary. This will enable local authorities to take stock of how the criteria are working for the benefit of carers.

86. Local eligibility criteria will enable local authorities to respond to need in their areas. There should, however, be a Scotland-wide approach so that local authorities take into account key drivers for support which would apply on a Scotland-wide basis. To that end, there is a power in the Bill to enable the Scottish Ministers to specify such matters by regulations. There would be full consultation on the regulations. It is important, for example, that support is provided on a preventative basis to prevent carers' needs from escalating so this "matter" i.e. preventative support to be provided could be set out in regulations. Referring again to the Borders example (in paragraph 12), the results from the quality of life questionnaire of carers

showed that early intervention and the preventative nature of the carer's assessment helps to meet the national performance indicators, particularly in terms of maintaining carers' independence, accessing appropriate support and building resilience.

#### *Benefits of the Bill*

87. The benefit of this approach is to ensure that local authorities can respond to the needs in their areas but under the umbrella of key Scotland-wide drivers for support.

88. If the Scottish Ministers come to the view that the local eligibility criteria are not working in the intended way, then under the Bill's provisions they could set out national eligibility criteria in regulations. Such national eligibility criteria would take the place of the existing local eligibility criteria.

### **Duty to provide support to carers**

#### *Current provision*

89. The current provision is as set out in paragraphs 81 to 83 above.

#### *Consultation response*

90. The consultation response is as set out in paragraph 84 above.

#### *What the Bill does*

91. The Bill will provide for both a duty and a power to support carers. Under the duty, the local authority will be obliged to support carers in accordance with eligible needs (i.e. those needs which cannot be met by general services and which meet the eligibility criteria). In determining which support to provide to carers local authorities need to consider, in particular, whether the support should take the form of a break from caring. Support for the purposes of carrying out this duty will exclude information and advice and universal services available in the community. It will also exclude services provided to cared-for person(s).

#### *Benefits of the Bill*

92. The benefit of this approach is that there is a firm statutory footing for supporting carers. Carers will be supported by what can be termed bespoke support under this duty. Bespoke support would include, for example, short breaks, training, advocacy and emotional support. Since not all carers will require bespoke support, these other carers will have access to information and advice and to the available community-based services. Of course, carers requiring bespoke support can also be supported by information and advice and by general services in the community.

93. The Scottish Government recognises the need to deal with the challenges caused where a carer's eligible needs can most appropriately be met through the provision of services to the cared-for person. This can be a particular issue where a carer is unable to take a break from caring without alternative care being provided to the cared-for person. The Bill confers a power on the Scottish Ministers to make provision about such cases.

94. It is essential that full consideration is given to whether access to short breaks will help to achieve the carer's identified personal outcomes (e.g. to support the carer to sustain the caring role and to have a life alongside caring). This is because a short break, which does not have to be a costly intervention, can support the carer in a meaningful way. Short breaks should include all manner of innovative and flexible provision as well as more traditional forms of provision. Some carers indicate that even having something such as a greenhouse can enable them to pursue an interest giving them a break from caring but being close enough to the person they are caring for. The Financial Memorandum sets out resourcing requirements for the duty to support carers and includes a short breaks component. Given the role that the third sector currently has in delivering short breaks, the third sector should continue to exert its influence over short breaks provision.

## **Carer involvement**

### *Current provision*

95. Section 12A of the 1968 Act provides for local authorities, in assessing the needs of persons for whom they are under a duty or have a power to provide, or to secure the provision of, community care services, to take account so far as it is reasonable and practicable to do so, of the views of the carer who provides a substantial amount of care on a regular basis. This is provided that there is a wish, or as the case may be a capacity, to express a view. There is similar provision in section 23 of the 1995 Act with regard to the carers of children affected by disability.

### *Consultation response*

96. All respondents supported carer involvement. Carers were regarded as being best placed to understand and comment on the services required for those they care for. The vast majority of respondents supported the involvement of carers' organisations in the planning, shaping, delivery and review of services.

### *What the Bill does*

97. Carers need to be fully involved in decisions about services that they have an interest in. The Bill makes provision for this. Both local authorities and health boards will be under a duty to take appropriate steps to involve carers in carers' services.

98. The duty to involve carers in carers' services applies where services have not been delegated under an integration scheme under the Public Bodies Act. Part 1 of the Public Bodies Act provides for integration schemes. An integration scheme means the key agreements of local authorities and health boards jointly that need to be reached in developing the integrated arrangements for health and social care. Where services have been delegated (or are to be carried out in conjunction with delegated functions) then the obligations imposed by the Public Bodies Act in connection with those functions are sufficient to ensure carer involvement. The Public Bodies Act therefore places obligations on integration authorities about carrying out functions which include obligations to involve carers and organisations representing carers.

99. The Bill also makes provision to ensure that the care provided by a carer is properly taken into account in any community care assessment for an adult or disabled child's assessment. It

places an express obligation on the local authority carrying out such an assessment to take account of the views of the carer about the extent of the needs of the cared-for person, whether those needs call for the provision of services and how any such services are to be provided. This provision recognises the degree of experience that a carer has in relation to the cared-for person.

100. The Bill amends the SDS Act so that local authorities will be required to have regard to the general principles set out in section 1 of the SDS Act when exercising functions in relation to the ACSP, YCS and the provision of support to carers.

#### *Benefits of the Bill*

101. The benefit of the Bill is that there is a legislative footing for involving carers in carers' services, which will make carers' services more responsive to carers' needs. The provisions will also replace narrower obligations that already exist about taking a carer's views into account in the current assessment provisions.

#### **Local carer strategies**

##### *Current provision*

102. There is no statutory provision for the preparation and review of local carer strategies.

##### *Consultation response*

103. Many respondents supported a duty to develop, publish and review local carer strategies. They saw merit in ensuring that unmet carer needs at the local level are identified, potential demand for services assessed, consistency in service provision promoted and progress in providing a range of services and achieving outcomes monitored and evaluated.

##### *What the Bill does*

104. The Bill provides a statutory basis for the preparation of local carer strategies. There are some local carer strategies in existence now, prepared by local authorities on a voluntary basis. There are fewer young carer strategies in existence. Where they exist, local authorities usually work with a wide range of partners, including carers, in their preparation.

105. The local carer strategy must set out the intended timescales for preparing ACSPs and YCSs. The Scottish Government will publish guidance on this in due course (as well as on many of the Bill's provisions).

106. The Bill sets out the consultative arrangements regarding the preparation of the local carer strategy. Since local authorities cannot consult all individual carers in the area, and since not all carers want to be consulted, the Bill instead is clear that local authorities must take appropriate steps to involve carers. In practice, local authorities will consult with groups of carers.

### *Benefits of the Bill*

107. The benefit of the approach in the Bill is that the provisions will enable a consistent approach across Scotland to various matters. These matters include the fact that the strategy must contain information relating to the particular needs and circumstances of young carers. The fact that there is provision for each local authority to publish its local carer strategy will ensure that all strategies are readily available for national and local interest. The review provisions whereby each local authority must review its local carer strategy at least every three years will also ensure that local carer strategies are reviewed on a regular but realistic basis.

### **Information and advice for carers**

#### *Current provision*

108. Currently, section 12AB of the 1968 Act and section 24A of the 1995 Act place local authorities under a duty to provide information to “regular and substantial” carers. This information relates to notification to the carer that he or she may be entitled to request an assessment of his or her ability to provide, or continue to provide, care for the person cared for or child.

109. Section 9 of the SDS Act places a duty on local authorities to ensure the provision of information and advice in relation to the self-directed support options. Section 10 makes similar provision in relation to children under the age of 16. The sections apply to carers as well as to service users.

#### *Consultation response*

110. Most, but not all, respondents supported the Scottish Government’s proposal for local authorities to establish and maintain an information and advice service. Some carers and carer organisations suggested that third sector organisations may be well-placed to provide and maintain locally based information and advice services.

#### *What the Bill does*

111. Carers need access to good quality, reliable and up-to-date information and advice. The Bill repeals section 12AB of the 1968 Act and section 24A of the 1995 Act and requires information and advice services to be established by local authorities for all carers (as defined by the Bill). Such services will need to involve health board and third sector interests and be fully co-ordinated and responsive to carers’ needs.

112. The Scottish Government is aware from research<sup>57</sup> that one of the barriers to short breaks for carers is lack of information about what is available. Therefore, each local authority has to prepare and publish a short breaks services statement. This will enable local authorities to provide information to adult and young carers about the different types and the range of short breaks that might be available.

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<sup>57</sup> IRISS, Shared Care & Coalition of Carers in Scotland (2012) *Rest assured? A study of unpaid carers’ experiences of short breaks*, Glasgow: IRISS. Available at: <http://www.iriss.org.uk/sites/default/files/iriss-rest-assured-full-report-2012.pdf>

### *Benefits of the Bill*

113. The benefit of the approach set out in the Bill is that there is clarity about what type of information and advice should, in particular, be made available to carers. A key part of this is information on carers' rights. It is always helpful for carers to have face-to-face interaction with advice workers who can support carers in a person-centred and helpful way. The Financial Memorandum therefore makes financial provision for the cost of advice workers who can provide one-to-one advice to carers on, for example, complex or detailed issues such as income maximisation or can talk with young carers about challenging issues such as the implications of the health conditions of the cared-for person or about support in school. The benefit of the short breaks services statement is that there should be readily accessible information to carers about the availability of short breaks.

### **Carer and cared-for person in different local authority areas**

#### *Current provision*

114. The local authority responsible for carrying out a carer's assessment is the local authority where the cared-for person is ordinarily resident or physically present. There may be some exceptions to this if a carer who lives in a different local authority area from the person they care for approaches, for example, their own local authority for a carer's assessment and that has been agreed. This is the interpretation of section 12AA of the 1968 Act. Local authorities will presently apply the legislation according to what suits them best and in a flexible way.

#### *Consultation response*

115. The consultation raised issues and posed questions about which local authority should prepare the ACSP and the YCS and provide support to the carer where the carer and cared-for person live in different local authority areas. The current arrangements vary across the country and are done on an ad hoc basis.

116. The response to the consultation was split with no consensus on this subject. Some respondents called for cooperation and collaboration between local authorities and some said that since there was a need for flexibility then the issue should not be covered in law.

#### *What the Bill does*

117. The Bill provides that the "responsible authority" is the local authority area where the adult carer resides. There are similar arrangements for young carers but adapted according to young carer circumstances. This means that the "responsible authority" in relation to a young carer is (a) where the young carer is a pre-school child, the health board for the area in which the child resides and (b) where the young carer is not a pre-school child, the local authority for the area in which the child resides. The Bill sets out other special cases of "responsible authority" as explained in the Explanatory Notes.

118. However, in certain justifiable circumstances, the function of preparing an ACSP and the function of providing support under it, should be capable of being carried out by another local authority, in particular, the local authority where the cared-for person lives. For example, the carer might require *in situ* training in moving and handling in the home of the cared-for person who is living in a different local authority area to where the carer lives.

### *Benefits of the Bill*

119. Since the Bill sets out a wide range of duties, mostly on local authorities, and since there will be more carers and cared-for persons living in different local authority areas due to family migration patterns, then the Scottish Government's view is that the Bill should set out the arrangements. Moreover, carers need to know which local authority to approach and to have assurances that they will not be passed from one local authority to another.

120. This approach means that, ultimately, responsibility for the ACSP and the support to be provided under it will remain with the local authority of the area where the carer resides. In practice, however, the Scottish Government envisages that certain parts, or indeed all, of the ACSP scheme can be carried out by, for example, the local authority where the cared-for person lives. This will be pursuant to arrangements made with the local authority in whose area the carer resides. Responsibility for the ACSP and any costs incurred in the provision of any bespoke support, such as a short break, would also remain with the carer's local authority. Arrangements could be made as at present, between local authorities for the recovery of costs.

121. This approach is to both provide reassurances to carers about which local authority is the "responsible authority" and allow for flexibility of approach as necessary.

### **Identification of carers**

122. Carer identification remains a challenge, as some people do not wish to be identified as carers at all, whilst others will initially reject the idea of identification only to seek identification later as the caring role intensifies with a view to receiving support. Many young carers do not present themselves for fear of stigmatisation and family break up. This is because many young carers want to be treated in the same way as other young persons who do not have a caring role although they do of course want support. Other young carers, especially if they are caring for a parent with mental ill health or substance misuse issues, do not want to be stigmatised by their non-carer friends or by services. The Scottish Government therefore consulted on ways to help support the identification of carers and young carers. The consultation confirmed that the Bill would not introduce legislative provision regarding the identification of carers. This is because it would be difficult to have a law about identifying people who may not know they are carers or who do not want to be recognised as such. The identification of carers is, however, hugely important as it is a prerequisite to assessment and support. Some areas have GP registers to help identify carers and some run publicity and advertising campaigns to help identify carers.

123. The Bill will, however, establish that local authorities must set out their plans for identifying carers within the context of the local carer strategy. Since local authorities must consult with health boards before preparing the local carer strategy then there will be a role for the health board in providing input on the role of GPs, hospitals services, community pharmacists etc. in identifying carers.

### **Monitoring and evaluation**

124. It is important that the Scottish Ministers know the extent to which the Bill is making a difference to the lives of carers across Scotland. The publication of the local carer strategies will enable the Scottish Government to obtain a view of the issues contained in all local carer

strategies. The Scottish Government will also put in place a comprehensive evaluation programme.

## **EFFECTS ON EQUAL OPPORTUNITIES, HUMAN RIGHTS, ISLAND COMMUNITIES, LOCAL GOVERNMENT, SUSTAINABLE DEVELOPMENT ETC.**

### **Equal opportunities**

125. An Equality Impact Assessment (EQIA) has been carried out and will be published on the Scottish Government's website. The Scottish Government considered the potential impacts, both positive and negative, across the protected characteristics required for EQIAs.

126. To develop and inform the EQIA the Scottish Government sought feedback from individuals and organisations or groups via the consultation process and is actively seeking feedback from related equality representatives through stakeholder engagement, including LGBT Youth, Scottish Youth Parliament, Alzheimer's Scotland, Minority Ethnic Carers of Older People Project (MECOPP), Coalition of Carers in Scotland, Carers Trust, Scottish Human Rights Commission and ENABLE Scotland.

127. The Bill's provisions will apply to all carers and there will be substantial guidance about the equality impacts. The national "matters" to be taken into account by local authorities regarding the local eligibility criteria could include the need to address the caring circumstances of carers with protected characteristics. The regulations setting out the "matters" will be subject to consultation.

128. Gaps have however been identified in the current evidence base around the effects of the Bill on some of the protected characteristics, for example, religion or belief, sexual orientation, pregnancy and maternity, and gender re-assignment. For example, it was stated at an engagement event that it is important to ensure that carers' specific dietary needs due to religion are properly taken into account when the carers are in support services. Another example is for statutory and third sector services to be fully aware that a LGBT carer is indeed the cared-for person's carer. These issues will be taken into account as the Scottish Government continues to create diverse ways of raising awareness of carers amongst different communities.

129. The EQIA concluded that the legislation will not directly or indirectly discriminate on the basis of age, disability, gender, gender reassignment, pregnancy and maternity, sexual orientation, race and religion or belief.

130. The Bill will make a meaningful difference to carers and will contribute towards the improvement of their health and wellbeing, ensuring that they can continue to care and to have a life alongside caring.

### **Human rights**

131. The Scottish Government is aware that positive steps may be appropriate to protect carers' rights under Article 8 (respect for private and family life) and 14 (prohibition of discrimination) of the European Convention on Human Rights. In extreme cases, it has been

argued that caring responsibilities could, without suitable support, have an impact on carers' rights under Article 2 (right to life) or 3 (prohibition of inhuman or degrading treatment). Those exercising functions under the Bill will have to exercise those functions compatibly with the Convention rights and the Bill provides a framework for those rights to be respected.

132. Specifically on the issue of data protection, some respondents to the consultation raised the issue of data protection in terms of the sharing of personal and sensitive information between and amongst various organisations. Having considered this in connection with functions under this Bill, there is no specific provision that requires to be made on the face of the Bill to regulate this. Responsible authorities will be required to carry out their functions under the Bill in a manner that respects both the common law duty of confidentiality and the Convention right to private and family life under Article 8 of ECHR. The Scottish Government's view is that, as framed, this Bill does itself not impose obstacles to or make any provision which threatens or undermines, or has the potential to threaten or undermine, respect for these rights. The Bill will allow provision to be made about the sharing of information for the purpose of an ACSP or YCS by regulations. Any such regulations would, of course, require to be compatible with Article 8 rights.

### **Island communities**

133. The Bill will apply to all communities across Scotland, including island communities. Argyll and Bute Council, Highland Council, Shetland Islands Council, NHS Ayrshire and Arran, NHS Highland, Western Isles Community Care Forum, Western Isles Carers, Users and Supporters Network and others with island community representation submitted formal consultation responses.

134. There are currently challenges experienced by island communities, for example, in carrying out the carer's assessment due to the need for extra travelling time and in delivering support services. There are examples of innovative solutions to help overcome the challenges presented by remoteness. One such example is the virtual carers centre run by Voluntary Action Shetland, which is supporting carers in many different ways.

135. The matters to be specified in regulations which local authorities must have regard to when setting local eligibility criteria would be subject to consultation. It could be the case that the matters should include consideration of the impact of remoteness and rurality when setting criteria. The Scottish Government would not want to pre-empt the consultation and it would also be helpful to take the views, prior to consultation, of carers living in remote and rural areas including island communities. It would be important, however, to consider the impact of geographical isolation on the cost of caring and the availability of support services.

### **Local government**

136. The Bill directly impacts on local authorities in discharging their duties as set out in this Policy Memorandum and in the other Accompanying Documents to the Bill.

137. Twenty three local authorities and six CHCPs submitted formal responses to the consultation on the Bill. Significant numbers of local government professionals attended the

national engagement event in Edinburgh in March 2014. Their remit covered both adult and young carers.

138. Engagement has been undertaken with COSLA both at Ministerial and official level. The Scottish Government has engaged with COSLA and specific local authorities during development of the Bill provisions.

### **Sustainable development**

139. The Bill will have no negative impact on sustainable development. It will have a positive impact on sustainable economic development by supporting those carers who wish to continue to care, safeguarding the estimated £10 billion of savings to the economy contributed by those delivering unpaid care. It will also ensure that carers can continue to have a life alongside caring. As set out in the Financial Memorandum, research<sup>58</sup> shows that due to the impact of caring, 5% of adult carers have left employment, 6% have been unable to take up work and 7% have worked fewer hours. For those who wish it, the support to be provided under the Bill's provisions will mean that some of these carers can continue in paid employment alongside their caring responsibilities. Research<sup>59</sup> has estimated that the public expenditure cost of working age carers leaving employment as a result of their caring role (in England) is £1.3 billion per year. If the Bill's provisions as implemented prevented, for illustrative purposes, 10 % of carers currently in employment from giving up work, based on the research's findings (pro-rata) for Scotland, cost savings to the public purse would be in the region of £13 million per year.<sup>60</sup>

140. The Bill provisions will have a strong positive impact on the health and well-being of the population of Scotland by ensuring that carers can continue to sustain their caring role in better health. It is well documented (and summarised at paragraph 17 et seq. of this Policy Memorandum) that "the intensity, duration and complexity of the caring situation has a profound influence over carers' health and well-being." The Bill's preventative approach to identifying carers and young carers, understanding their personal outcomes and needs for support is focussed on ensuring that carers receive the support they need well before reaching any crisis point.

141. It is considered that the Bill will have minimal effect in relation to the environment and, as such, is exempt for the purposes of section 7 of the Environmental Assessment (Scotland) Act 2005.

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<sup>58</sup> Scottish Health Survey 2012-13

<sup>59</sup> Dr Linda Pickard et al (2012) *Public Expenditure Costs of Carers Leaving Employment*. NIHR School for Social Care Research. Available at: <http://blogs.lse.ac.uk/healthandsocialcare/2012/04/25/dr-linda-pickard-public-expenditure-costs-of-carers-leaving-employment/>

<sup>60</sup> This is a speculative saving, some of which would accrue to HM Treasury and some to the Scottish parliament when powers over the carer's allowance are devolved.



*This document relates to the Carers (Scotland) Bill (SP Bill 61) as introduced in the Scottish Parliament on 9 March 2015*

# **CARERS (SCOTLAND) BILL**

## **POLICY MEMORANDUM**

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