



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

16<sup>th</sup> April 2014

Dear Alun

**“Always, always a duty. If left to guidance it will never happen.”**

Response to NCO online survey on the proposed Carers Legislation

Thank you for the opportunity to respond to the consultation on proposals for new Carers Legislation. We very much welcome the Scottish Government’s commitment to build on the progress that has been achieved in recent years, and to find further ways carers and young carers can be supported through new duties and legislation.

We worked closely with colleagues across the National Carer Organisations (NCOs) to promote the consultation to our networks, and together we have provided opportunities for people to contribute their views through a series of regional events arranged by the NCOs, Scottish Government and other organisations. At least **460 people** attended these events which is perhaps a clear indication of the enormous level of enthusiasm for new legislation to improve rights for carers. People were also able to engage with the consultation through an online survey which received **104 responses**, social media and many will have fed back directly via the Scottish Government’s own consultation mechanisms.

By way of background, Shared Care Scotland is a national charity that works to improve the quality and availability of short breaks (respite care) for unpaid carers and the people they care for. We provide information and advice to help people navigate their way to suitable short break services and we run events and learning exchanges to promote good practice. We also undertake and

Unit 2, Dunfermline Business Centre, Izatt Avenue, Dunfermline, Fife, KY11 3BZ

[www.sharedcarescotland.org.uk](http://www.sharedcarescotland.org.uk)

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commission research to help inform policy development and since 2011 we have managed, on behalf of the Scottish Government and the NCOs, a Short Breaks Fund grants programme distributing £2.3m per year to third sector short break providers.

The purpose of this letter is to respond specifically to the questions raised in the consultation document about the development of a Short Breaks Duty. Our views on the wider legislative proposals have been incorporated into the National Carer Organisation joint response.

### **Short Breaks Duty**

With regard to Question 11 in the consultation paper – *Should we introduce a Short Breaks Duty?* – our response is a firm ‘Yes’.

**There was more or less universal agreement on this from carers and those attending the consultation events, and 95% of the online survey respondents also agreed. A separate survey of parent carers carried out by Children in Scotland, on behalf of ‘For Scotland’s Disabled Children’ produced a similar response of 92% (of 248 total responses) in support of a Short Breaks Duty.**

We appreciate there may be resistance from some quarters to the introduction of further statutory duties and so we would like to set out our reasons why we think this is a very important and necessary development.

Various research studies have shown that providing effective short break services for carers delivers social and economic benefits, saving public money in the long run, for instance by reducing the need for long-term residential care, decreasing demand for health services due to reductions in stress, and improving the health and wellbeing of carers and those they care for.<sup>1</sup>

Recognising these benefits, Scottish Government and COSLA Guidance on Short Breaks published in 2008 set out to persuade local authorities and their partners to work strategically to develop ‘greater choice, flexibility and equity in the provision of short break services’.

However, the most recent evidence available tells us that progress against these objectives has been ‘patchy’ and the lack of a clear statutory context for short breaks at the local level continues to leave services extremely vulnerable to public sector budget pressures.

Despite some important improvements delivered under the National Carers’ Strategy<sup>2</sup>, the availability of short breaks remains limited and variable often being viewed as “the icing on the cake” rather than as an essential support service for carers and those they care for.

We believe that a Short Breaks Duty within the proposed Carers Legislation will help safeguard the progress that has been achieved in many areas, but will also ‘accelerate’ short break improvements elsewhere so that more individuals and families with caring responsibilities are able to have a good quality life outside of their caring role.

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<sup>1</sup> Research references can be found in, ‘Caring Together – The Carers Strategy for Scotland 2010-15, Scottish Government, COSLA

<sup>2</sup> Caring Together and Getting it Right for Young Carers – The Carers Strategy for Scotland 2010-15, Scottish Government, COSLA

The Duty would not establish a minimum entitlement to breaks from caring along the lines of the SNP government's 2007 manifesto commitment – *“By 2011 carers in greatest need will have a guaranteed annual entitlement to breaks from caring.”*<sup>3</sup> However we believe it will help deliver a more consistent and coherent approach to short breaks planning leading to greater transparency, equality of access and accountability.

Along similar lines to the Short Breaks Duty in England<sup>4</sup>, we would like local authorities to use this new Duty to establish a range of short break opportunities that meet the needs and aspirations of eligible individuals and families. This would include:

- Provision that is available overnight and through the day
- Recreational activities, leisure activities and holiday provision
- Short break services available to assist carers in the evenings, at weekends and - particularly for parent carers - services available during the schools holidays

We would like to see the Duty supported by guidance that provides detail on how local authorities are expected to deliver their responsibilities, taking into account the broad spectrum of caring circumstances. The 2008 Scottish Government and COSLA Guidance on Short Breaks (Respite) is still relevant and therefore a good starting point for the development of the new Duty.

We would also like to see this Duty set alongside a wider Duty of support which would ensure carers received any additional advice, information and practical support they may need to continue to care, and to allow them to do so more effectively, safely and in good health.

### **Resourcing a Short Breaks Duty**

The Duty should not result in unrealistic costs falling on local authorities (and in any case these must be weighed against the long term savings that will be achieved). Some local authorities will already be broadly complying with the requirements; others will be close and will make progress through more effective and efficient use of their existing resources, both financial and non-financial. However we do recognise that local authorities will wish to be reassured that central government will help to meet any additional costs associated with the implementation of the Duty, which cannot be met by reconfiguring existing budgets.

We would expect a Short Breaks Duty to act as a catalyst to encourage local authorities and their planning partners to work together to develop new, creative ways of using their resources. There will be a stronger incentive to expand the development of mainstream services for short break purposes, and to explore the establishment of community-led opportunities such as volunteer befriending or family placement, where relatively small investments can generate additional capacity. It will lead to more robust review and evaluation which will help ensure resources are delivering the best outcomes possible.

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<sup>3</sup> SNP Manifesto 2007

<sup>4</sup> Since April 2011 local authorities in England have had a Duty to provide short breaks under Children Act 1989, Breaks for Carers of Disabled Children Regulations, 2011

There is evidence that the development of a Short Breaks Duty in England has stimulated new forms of service development and is saving money:

*“Our short break programme has delivered not what we thought people needed, but what people actually wanted. As a result we have delivered a hugely successful programme at a low cost per unit price. We have supported more families and made progress on our strategy of reducing high cost residential places. If we reduce just one place per year a saving of around £220,000 will be made. As disabled children currently in residential placements move to adulthood we will see a real reduction in placement costs of potentially £500,000. In consultation with parents we have invested substantially in a broad range of short breaks based in the voluntary sector. This has already reduced the number of placements made in crisis and the costs of formal assessments. If we can develop this trend we are confident, and research supports this, that we can reduce our high costs cases substantially.”*

Paul McGinney, Commissioning Manager from Durham

### **Short Breaks Statement**

The consultation also refers to a Duty to develop and promote local Short Break Statements. This would make local authorities responsible for the promotion of information about the availability of short breaks, and for actively helping carers understand how they can access them.

We strongly support the development of local Statements as part of the Short Breaks Duty. This was positively supported by those attending the consultation events, and by those responding to the online survey.

A detailed specification for a Short Breaks Statement will have to be developed, but as a minimum we would like to see Statements contain:

- Details of the range of local short break services and support available
- Any criteria against which the eligibility for services will be assessed
- An explanation of how the range of services and supports available has been designed around what people need and want
- Information about continuity of support through age and stage transitions
- An up-to-date list of key contacts for information and assistance on short breaks
- A named lead contact with responsibility for the Short Breaks Statement
- (Separate statements will be needed for Children’s services and Adult and Older People’ services.)

We know from the consultation events that information is key to giving carers and the people they care for greater control over decisions and outcomes – helping them to feel more empowered. We believe the Short Breaks Statement will be a vital tool to help carers understand what short breaks are available in their area, and which breaks they may be entitled to. Carers report great difficulty in finding this information.

*“Six years into my husband’s terminal illness I have only just been informed that I’m entitled to 6 weeks council funded respite care a year.”*

Response to NCO Carers Legislation consultation

In England, where Short Breaks Statements have been in place since 2011, there is good evidence emerging this is making a positive difference:

*“EDCM analysed 55 short breaks services statements and the findings of our research are extremely encouraging...a marked improvement in local provision of short breaks, in transparency and in information provision. As a result it is clear that this ‘Duty to provide’ has acted as a positive catalyst for cultural change, and policy and practice improvement in a wide range of LAs.”<sup>5</sup>*

We agree that the legislation should also include a Duty on local authorities to establish and maintain a service for providing people with information and advice. This will be key to people being properly informed about short breaks and signposted to the different options that may be available to them, as well as other information and sources of practical help.

However we believe the emphasis here should be on local authorities having a Duty to establish and maintain a local infrastructure of support organisations that provide information and advice in an accessible, personal and timely fashion. An online or ‘virtual’ service, or the publication of a carers leaflet, would not go far enough. Carers routinely tell us how much they value being able to speak to someone in person as they may need guidance on what information will be helpful to them. It is important too that independent advice and information is available.

We are concerned at proposals to repeal Section 12 of the Community Care and Health (Scotland) Act 2002 until it is clear what will be put in place to ensure the continued development of Carer Information Strategies post integration, and how funding around this work will be secured.

### **Eligibility Framework**

The consultation paper proposes that any Duty to support carers would need to be linked to an eligibility framework.

We accept that resources may need to be prioritised to those experiencing the greatest difficulties. We therefore understand the need for assessment and eligibility frameworks, but these must be fair, transparent and consistent. However carers attending the consultation events raised a number of concerns about the use of eligibility criteria locally as a means of controlling expenditure - by raising thresholds - at the expense of focusing on prevention and enablement.

*“... it is important that the eligibility framework is not placed at too high a level meaning many carers would be ineligible for support. Any framework should be produced jointly with carers and be at the ‘national’ level not just local which could lead once again to post code lottery support plans.”*

*“It is very difficult for people on the outside of a situation to be able to assess the needs and requirements. The important thing is to recognise situations which could put people at risk of reaching crisis point –regardless of their position on any framework. Preventative support is vital.”* Two responses to the NCO Carers Legislation consultation

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<sup>5</sup> Short Breaks Services Statements: Commitment and Transparency, Every Disabled Child Matters, 2012

If the legislation is to lead to improved outcomes for carers - to have the ability to combine caring responsibilities with work, social, leisure and learning opportunities and retain a life outside caring - then any eligibility framework developed must be balanced towards early intervention. We would therefore wish to see carers and carer organisations closely involved in the development of the eligibility framework, and any accompanying guidance and regulations.

The paper goes on to say that a Duty to support would not prevent local authorities using their new discretionary powers to support carers and young carers where they do not meet the criteria for the eligibility framework.

Linked to this, we believe there is merit in local authorities developing a Local Offer approach. This would provide a stated minimum level of short break provision that is universally available, without the need for an assessment. Eligibility could simply be determined by being registered at the local carers centre – or being known to other support services.

An advantage of the Local Offer is that many people will be able to access a relatively small level of support that meets their needs, which may prevent their needs escalating and requiring more in depth assessments and possibly increased local authority intervention. A Local Offer will suit many families as it will enable them to lead an ordinary life, as far as possible, without feeling ‘dependent’. It also allows local authorities to deploy scarce resources for assessment to where they are most needed

A Local Offer could for example include the availability of short break vouchers that can be used flexibly by carers to have a few hours to themselves, access to a children’s activity programme over the summer holidays, and the assistance of an advisory service to help source accessible holiday opportunities. Efforts to make mainstream leisure and recreation services more inclusive will contribute to expanding the Local Offer.

## **Engagement**

We agree that carers, as equal partners in care, must be at the centre of decision making and therefore we support the proposal within the Discussion Paper (Chpt 6, Section 13) that legislation will reinforce the principle of carer involvement in care planning, both in relation to the person they care for and their own support. We also support carer engagement at a more strategic level in contributing to the shape and future direction of services, which would include their involvement in the development of short breaks and the Short Breaks Statement.

*“Investment in carers and carer engagement will bring many valuable returns – stronger planning and policy, improved services, more creative use of resources and improved outcomes for carers.”*

Equal and Expert: Best Practice Standards for Carer Engagement,  
Coalition of Carers in Scotland, 2013

We would also expect there to be provision for the cared for person to be properly involved too. Their experiences and opinions of services are just as important. This is particularly the case in the planning of short breaks where provision needs to be designed and delivered to achieve good outcomes for both.

To conclude, we would refer back to the Care 21 Report into the Future of Unpaid Care in Scotland, published by the Scottish Executive in 2006. The report promoted an emerging vision for carers which included:

*“By 2014, carers will be entitled to regular breaks from caring and have ready access to practical support.”*

It is only right that carers should have broadly equal access to a break regardless of where they live or which ‘group’ they belong to, but we know that people in similar caring circumstances living in different parts of Scotland have significantly different experiences of accessing short breaks.

*“I don’t know how they decide if I’m going to get a break or if I’m not going to get it. My own opinion is the ones that shout the loudest, get!”<sup>6</sup>*

Eight years on from Care 21 we believe the development of new Carers Legislation will provide us with a key opportunity to move forward and to ensure that carers, irrespective of where they live, have the best chance of receiving the breaks they deserve.

Yours sincerely



Don Williamson  
**Chief Executive**

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<sup>6</sup> Rest Assured – A Study of Unpaid Carers’ Experiences of Short Breaks, July 2012, Shared Care Scotland/IRISS