

PE1499/E

Cabinet Secretary for Health and Wellbeing

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Dear David

PETITION PE1499 ON CREATING SUITABLE RESPITE SERVICES FOR YOUNGER DISABLED ADULTS WITH LIFE-LIMITING CONDITIONS

Thank you for your letter of 28 November 2013 regarding the above petition. The Committee also wrote to Paul Gray, Chief Executive, NHS Scotland on the same matter. On the advice of the Assistant Clerk of the Committee provided to officials, the issues raised in both these letters are covered by this reply.

The Scottish Government recognises the vital importance of respite care and fully supports the provision of short breaks for individuals with care needs and the people who care for them. This was made clear in the joint Scottish Government/COSLA strategy, Caring Together, The Carers Strategy for Scotland 2010-2015.

The Government has long had an interest in respite care and there is a Manifesto commitment to maintain an additional 10,000 respite weeks each year. Taking into account changes in methodology of data collection, it is estimated that the number of respite weeks provided in Scotland has increased by 12,650 weeks (7.3%) in real terms between 2007/08 and 2012/13.

An annual survey of all local authorities in Scotland provides information about the respite care services each council purchases or provides. The latest published figures are available online at:

<http://www.scotland.gov.uk/Topics/Statistics/Browse/Health/Data/Carers>.

However, I recognise the additional challenges to the provision of respite care for younger disabled adults as a result of the decision by Children's Hospice Association Scotland (CHAS) to establish an upper age limit for its services.

According to the documents supplied by CHAS, it sees an increasing number of young people who now live into adulthood when previously they may not have been expected to. CHAS had been considering the right time to start the process of transition from a children's hospice to adult services and concluded it should introduce an upper age limit of 21. For any CHAS young person near or beyond the age of 21 years, transition will happen over 3 years.

In 2011 the regulation of in-patient hospice services was transferred from the Care Commission to Healthcare Improvement Scotland (HIS). The position of HIS was that Rachel and Robin House, as independent healthcare providers, were set up to provide specialist palliative care to patients under 18 years and this was reflected within the registration certificates. Both hospices were asked to apply for a variance to registration to ensure CHAS complied with regulatory requirements in relation to age. The variance was confirmed in December 2011 to include the condition that: "The service will operate as voluntary hospices providing specialist palliative care to children and young adults up to the age of 35 years". CHAS considered this only to be a temporary situation whilst the issue of a possible upper age limit was discussed. The age limit of 35 years was agreed as the oldest adult accessing CHAS services was 31 years old at that time and a 4 year lead in time was anticipated in terms of transition. In 2012, CHAS was supporting 32 young people who were aged 18-20; and 34 people aged over 21.

The vast majority of funding for short breaks/respite is provided by local authorities putting in place services for service users where carers benefit indirectly from the replacement care provided. The Scottish Government has also provided £29 million to Health Boards between 2008 and 2015 for Carer Information Strategies, some of which is supporting short breaks provision mainly provided by the Third Sector.

Through the voluntary sector Short Breaks Fund managed by Shared Care Scotland and the Family Fund, the Scottish Government has allocated over £13 million to the Third Sector between 2010 and 2015. This comprises the Better Breaks programme and the Take a Break programme for disabled children and young people up to the age of 20 and their carers and Creative Breaks for other caring situations. We have recently enhanced the Short Breaks Fund with £250,000 to help carers of children and adults with learning disabilities to have a break from caring.

Local authorities, with partners, have responsibility for assessing need and demand for short breaks for carers. The voluntary sector Short Breaks Fund is a relatively new innovation that was launched with the Carers Strategy in 2010. The Scottish Government asked one of the National Carers Organisations, Shared Care Scotland, to administer the Fund on its behalf. The UK-wide organisation, the Family Fund, is also now involved in administering the Take a Break fund in Scotland. This provides grants directly to the families of disabled children and young people. The key principles and criteria of all parts of the voluntary sector Short Breaks Fund are agreed with the Scottish Government. The purpose of Better Breaks, Creative Breaks and Time to Live is to improve the range, choice and availability of short breaks so that carers and the people they care for have a better quality of life and feel better supported in their caring relationship. The guidance developed for the Fund (Better Breaks, Creative Breaks and Time to Live) makes clear that the voluntary sector fund should not replace statutory funding or pay for statutory responsibilities. The Family Fund's short breaks scheme

must dovetail, as far as is reasonable practicable, with the funds administered by Shared Care Scotland.

The funding available for the voluntary sector Short Breaks Fund is relatively modest but is achieving a lot for carers and cared-for persons. Nevertheless, since most carers need access to regular, personalised breaks from caring in order to sustain them in the caring role, there is a need for a coherent and sustainable approach to short breaks at local level.

The Government believes that some of the barriers to the effective provision of respite care will be reduced by our commitment to more integrated health and social care. The Public Bodies (Joint Working) (Scotland) Bill, which provides the legislative framework for integration of health and social care planning and provision in Scotland, is currently at Stage 2 of the Scottish Parliament legislative process. The new legislation will place requirements on Health Boards and Local Authorities to develop joint strategic plans that focus on preventative and anticipatory care, and the wellbeing of patients, service users, carers and families, within the context of national outcomes for health and wellbeing that are defined in legislation and integrated budgets for health and social care. Health Boards and Local Authorities will integrate health and social care services from April 2015; local partnerships are now establishing shadow arrangements.

This framework for integration responds to the changing needs of Scotland's population, particularly in terms of people living for longer with multiple complex needs, by enabling partners from the public, third and independent sectors to work together more effectively, with service users and carers, to plan for and provide services that take account of people's broader circumstances. Our priority is to ensure that people receive the right care, at the right time and in the right place, and to support people to live well, safely, and as independently as possible, at home, for as long as possible. Availability of appropriate respite support will play an important role in that objective, as will ensuring a full role for local professionals and communities in integrated locality arrangements. By planning together for the whole journey of care, within the context of total available resources for health and social care, local partners will under the new legislation be well-placed to prioritise preventative care via community-based support. The legislation will require local integrated health and social care partnerships to publish annual performance reports.

As I outlined in response to a recent question by Jim Eadie MSP, the Social Care Self-directed Support (Scotland) Act will also contribute to the provision of respite care. This Act places a duty on authorities to offer all eligible social care clients a range of choices in relation to their community care support. This includes the provision of respite support. Direct payments or individual service funds – a new option under the SDS Act 2013 – offer an alternative to traditional forms of respite. They provide the adult with the opportunity to develop a wider range of respite options which are more appropriate to their needs, age, peer group, interests and personal outcomes.

For instance, the young adult can accumulate respite funding and use it as a direct payment or individual fund for the purchase of more expensive respite arrangements; the adult can use the direct payment to purchase support from a personal assistant of their choice; a group of young people can pool their direct payments to purchase joint respite activities which are relevant/of interest to them.

In his appearance before the Public Petitions Committee, Mr Watson mentioned Leuchie House in East Lothian as a potential facility for short breaks for young adults. However,

he also mentioned the cost of a stay at Leuchie. Leuchie House primarily provides care and support in the form of a short break for people with neurological conditions. They do this for people wherever they live in Scotland. We have however spoken with Leuchie who advised that they have provided a short break for a few young adults with life limiting conditions. Whenever an individual thinks that Leuchie might be able to support them, they (and their carer(s)) should contact Leuchie to see what might be possible. Staff at Leuchie will talk through a wide range of issues including levels of dependency, needs and what the individual would like from his or her stay at Leuchie. Mostly, Leuchie will be able to provide a short break but there could be a few circumstances where a decision is made that Leuchie is not the most appropriate place for the individual. Leuchie provides 24-hour nursing support but where specialist or niche nursing is required, Leuchie will liaise with specialists and training will be provided.

On the issue of the cost for a stay at Leuchie, individuals and carers should always discuss these issues with the local authority and Health Board. Moreover, local carers centres can advise on funding packages too where the need for a break has been identified within the individual's assessment. Staff at Leuchie can also advise on funding packages.

We do not know if Mr Watson or his family have contacted Leuchie directly to discuss these issues. We recognise, however, that Mr Watson's concerns are primarily for a dedicated service for young adults with life limiting conditions. We have however provided this information as it might be useful in the context of overall provision for young adults.

As commissioners of care, local authorities and NHS boards have a statutory responsibility to determine the requirements of local services and to provide or commission services. Each local authority and health board decides on its own priorities and how best to address the need for respite. We will explore the issues raised by the petition and the potential solutions with COSLA and other stakeholders.

I hope that you will find the information in this letter helpful.

ALEX NEIL