

PETITION PE1499 - Response letter to written submissions

First of all we would like to thank all those who have replied to the Committee about this very important issue. We do agree that there are a number of challenges that need to be overcome to achieve our goal, but none of these are insurmountable.

Response from the Muscular Dystrophy Campaign (MDC)

The response from the MDC was very positive, they fully agree with and support the petition (*“new provision must be established as a matter of urgency”*), and they back up everything that we have been saying throughout the campaign. Crucially, they back it up with some statistics taken from the survey they have been conducting into Hospice and Respite Services in Scotland. These sort of statistics are vital in backing up our argument when trying to convince those who don't seem (or aren't willing) to see that this is a big problem which needs dealt with.

Response from the Scottish Partnership for Palliative Care (SPPC)

The response received from the SPPC is very helpful. They are fully supportive and in agreement with the issues that the petition raises, and they go into good detail about the reasons why this has become a problem, the history of how long this gap in provision has existed for (which is good because we had not previously been aware of this) and they offer some constructive suggestions as to how we take this forward and deal with the barriers.

Responses from COSLA and Midlothian Council

I wish to group these two responses together because strangely, both responses appear to be almost word-for-word identical. Both of these respondents appear to be quite against the premise of the petition. The following are points that were raised in both letters that we wish to comment on:

“With the introduction of Self Directed Support and the existing Direct Payment system there is a move away from the use of dedicated facilities to more use of flexible support and alternative solutions to the need for respite arrangements.”

and

“There is a move away from the use of fixed buildings, where possible, which is at odds with the premise of the petition.”

We would like to know what evidence they have to back up this statement about the “move away from the use of dedicated facilities” and “fixed buildings”? Self directed support will not suddenly mean that dedicated respite facilities will not be required. If it is about giving people more choice and control, why give people less choice by removing the option of dedicated facilities? For SDS to work local authorities and health boards need to work together to facilitate and promote a variety of short break options to offer real choice to meet different needs and circumstances – what alternatives do they see as viable solutions? There is no reason why people couldn't have a highly personalised building-based service (residential or day) where people could come together to plan their days and activities. Of course there are cost implications but it is not right to use SDS as a

justification for disinvesting in facility based provision without clear evidence that people want something different.

According to statistics gathered so far from the survey that the Muscular Dystrophy Campaign has been conducting into Hospice and Respite Services in Scotland,

“70% of respondents very strongly agree that the impact would be terrible if respite/hospice provision in the area was stopped”, and “70% of those responding strongly agree that these services are vital for their families’ quality of life”.

This very strongly backs up our campaign group's feeling that dedicated respite facilities are still very much needed and valued by disabled people and their families. Also a recent study into Duchenne found that only 8.1% of adults lived on their own in the UK compared to 20.7% in the rest of Europe. Those who live independently are unlikely to require respite facilities (although some still might), but as this statistic proves only a small number live independently, which means the vast majority of people still live with their families and therefore still require the support of dedicated respite facilities.

One of the main reasons that CHAS had to introduce an Upper Age Limit was because of the pressure being put on their facilities due to the demand in people who wanted to use them for respite. This would not be the case if people were moving away from such facilities.

“Creating a new respite facility for this specific client group would be expensive and before such a facility could be developed it would be important to assess the level of demand to see if setting up such a service was justified. It will be important to make sure that if such a facility was set up it would be used fully.”

and

“if demand for such a service is low a facility could end up being created to cater for only one or two people at one time.”

Such a facility would certainly be used fully. Demand for such a service is very high, so there is no risk that such a facility would be underused. As I said CHAS's facilities were becoming over crowded because of the demands for their services, and now that they have introduced this age limit, over 100 young adults and their families are looking for new respite facilities. But as well as this number, there are others who haven't been able to use CHAS's services but who still would make use of other respite facilities if they were available. Given improvements in care and life expectancy for those with neuromuscular conditions, and as the years go by and more young people reach the cut off age of 21 (and who knows, in the future this might even go down further, to 18), the number of young people needing age-appropriate adult respite services is only going to keep increasing. Also, this issue affects not only young adults with neuromuscular conditions, but all young disabled adults affected by many different conditions, for example Multiple Sclerosis. So overall you are looking at many thousands of young people and families who really need dedicated respite facilities. We do not have access to exact statistics however. Perhaps this is an area the Committee could investigate?

Midlothian Council said:

“Within Midlothian demand for this type of specialist provision would be extremely small making the development of such a resource within our area unfeasible. I

imagine many geographic areas would have similar issues. Due to the limited nature of the demand Midlothian would not wish to contribute to a national contract for such a service and would commission on an individual basis. “

And COSLA said:

“If an adult facility was set up there is no guarantee that local authorities would enter into a national funding agreement such as exists with CHAS, those local authorities using such a service might prefer to pay for services provided directly.”

It is true that in some areas where demand isn't as high this could be an issue, as the Scottish Partnership for Palliative Care (SPPC) say in their response, *“the relatively small numbers of people affected in each local authority may make dedicated local facilities difficult to finance and sustain”* So this is another reason why a national solution would be a better option, but this does require local authorities to work together – to quote the SPPC it would *“require complex partnership across multiple NHS Boards and Local Authorities and there will be a need for a “lead broker”, with the resources to carry out complex and potentially protracted work”*.

Also, as the Muscular Dystrophy Campaign says:

*“The Cross Party Group discussed the need to bring together organisations from across the spectrum in order to establish a solution, including patient organisations, the Scottish Government, Health Boards and hospice providers. The Muscular Dystrophy Campaign supports this call and we want to work constructively with all these organisations. In particular, we wish to ensure that any solution is a long term one. To this end, **we see an important role for Health Boards across Scotland in funding alternative provision**, as this would provide long term security for these vital services.”*

So in short, a solution is unlikely to be found without everyone working together and pulling in the same direction. The demand isn't low in every local authority area either, as I have already shown above there is a large demand for adult respite facilities and some local authorities have a large amount of people in their area who would benefit, for example Greater Glasgow and Clyde health board.

“The setting up of such a service might have knock on effects to existing respite services and make them unviable.”

We fail to see how this would be the case. How would it make existing respite facilities “unviable”? We would like to know what evidence COSLA and Midlothian Council have to back up this statement.

“Currently respite care for adults is generally paid for by social work departments with a contribution by the NHS depending on the level of care needs of the individual, some charges may be made for respite but they do not cover local authority's costs.”

This is something we agree on, there needs to be a larger contribution from the NHS to help fund respite care. We agree with the SPPC that *“whilst the financial costs of respite care fall on Local Authorities (and also on individual members of the public and voluntary organisations), the financial benefits tend to accrue to the NHS (in so far as respite care supports the health of the carer and prevents crisis admissions to hospital). It is to be hoped that ongoing moves to health and social care integration will address this issue of*

resource allocation.” This is where we need the assistance of the Scottish Government, who talk in their response letter about their “commitment to more integrated health and social care”. However, this integration will not in itself lead to improved respite care support, it will very much depend on to what extent this is considered a priority. Obviously it is our view that this very much should be a priority.

“One comment received from our local authority contacts was the equalities challenges around creating such a specific service for an age specific group, as they thought this might be unjustifiable within the boundaries of the Equality legislation.”

This was a comment that none of us understood, because most of these type of services are designed for a specific age group. Indeed what gave rise to this campaign was the fact that CHAS have made their services age specific by introducing an Upper Age Limit. The majority of children's hospices are age specific, and at the other end of the scale there are specific services designed specially to cater for elderly people. The reason we are doing this is because adults are not given the same provision as children even though their need is potentially more. We are just looking for something in the middle, which as a few of the respondents also agree, is a gap which desperately needs to be filled, and it has been a problem for some time. As the SPPC states, “the issue is not a new issue”. We don't understand how or why equality legislation would come into it.

“It would be necessary to find out if there is a charitable organisation prepared to set up such a facility for adults between the ages of 21 and 41.”

As the above quote from COSLA and Midlothian Council states, perhaps it might be more feasible to work with an organization or a charity who would be willing to help solve the problem, rather than starting up from scratch. For example the Prince & Princess of Wales Hospice is quite keen to support younger adults with severe physical disabilities, but in order to do this they would need significant financial support, so again this is an area where government support could be vital. Is this an avenue the Committee could go down? Perhaps they could set up a small working group to investigate the options?

“we recognise the value of respite care, we are just not sure if building a model for this specific group is the best option.”

We would like to know then, what do COSLA and Midlothian Council believe is the best option for “this specific group”? If they are unsure, they just need to speak to those of us who are affected by the lack of age-appropriate respite facilities and look into the statistics (such as the ones gathered by the MDC which I mentioned earlier) and they will surely be left in no doubt as to what we require.

Response from the Scottish Government

Some of this response is not relevant to the specific issues described in the petition, for example Mr Neil talks about services provided for young people up to the age of 20 and for those with learning disabilities – this information does not help when we are talking about support for those aged 21-45 who have severe physical disabilities. Also some of the letter talks about support for carers without acknowledging the problem of what happens to the person they care for whilst they are away on their break? Most physically disabled people I know would not be content to stay at home looking at the same four walls as usual except with a paid carer while their parents/regular caregivers are away on their break, as this does nothing to solve our feelings of social isolation.

The overall respite weeks data Mr Neil presents in the letter does not tell the whole story. Certainly it shows an overall increase in the volume of breaks provided but this overall figure masks the significant variation that exists between local authority areas. Looking more in depth at the figures using the website link he provides, some areas have certainly increased provision, but others have not. Also the data does not give any detail on levels of unmet need so we have no idea to what extent an additional 12,000 weeks is actually making a difference in the grand scheme of things.

It is good to read of the money that the Government has allocated to the Short Breaks Fund, but taken individually each of these are just small grants that are given as a one-off payment or for one particular project. However what we require is something that provides a more guaranteed, regular level of funding to maintain the respite service, basically something which is based on the CHAS model of care except for younger adults.

Mr Neil provides some useful information that I wasn't aware of when talking about the SDS Act and the options it offers. It is useful to know that there is money that can be provided, but there is no guarantee that the money will come close to covering the cost of some respite facilities, nor that it won't become a postcode lottery where some local authorities are prepared to provide enough funds but others are not. The biggest point however, is that it is all well and good being given this money to spend on respite activities but, and this is the whole point of our petition, this is of no use when there are no age-appropriate respite activities/services for our age group and disabilities to make use of!

He does however make an important point about the need for more systematic and coherent planning of short breaks at the local level to ensure that all the available resources are being used to the greatest effect. This relates to the point I raised earlier about the local authority and health board role in proactively working with carers/service users and providers to maximise the impact of their resources – both financial and non financial. We need to try and make sure that local authorities acknowledge their responsibilities and work together with one another to try and come up with a solution that works for all, regardless of where they live.

Regarding the point in the letter about Leuchie House, my family and I have been in discussions with them and have even been to visit the facilities, but none of the funding support options would cover more than a fraction of the cost of a stay – for someone with a severe physical disability who has high support needs, it costs approximately £1000 for a 4 night stay, which I think the Committee will agree is far too expensive.

We do appreciate the time Mr Neil has spent in writing such a detailed response to us. It is encouraging to see that the Scottish Government recognise what our primary concern is and that they agree that respite care is a very important issue. He talks about many positive commitments, priorities etc. in the near future, this is also encouraging but will it lead to the real changes that we require, or will it just pay lip service? This last comment does give us hope:

“We will explore the issues raised by the petition and the potential solutions with COSLA and other stakeholders”

We will await these developments with interest, and hopefully they will come round to our view that the best solution is the one we have said we require all along – namely a dedicated facility for younger adults with severe physical disabilities.

To finish off I would like to say that I, along with everyone else on the campaign group,

were delighted with the suggestion from the Petitions Committee after our presentation to them in November that this issue be debated in the parliament and we are extremely keen for that to happen. Some of the agencies and organisations who are working with us are working to provide data that would scope need and would help in supporting a debate in the chamber.

Robert Watson, on behalf of the “What About Us?” campaign group
10 February 2014