



**Coalition of Carers in Scotland
&
Highland Community Care Forum**

**Carers' Views on, and Experience of,
Respite Care and Charges for the Service
in the Rural Areas of Highland**

March 2009

Contents

Summary	3
Introduction	5
What the Carers Said	8
• The Value of Respite/Short Breaks to Carers	8
• Value to Cared-for Person	10
• Difficult Aspects of Respite Care	10
• Carers with No Experience of Respite Services	11
• Charging for Respite Care	11
• The Impact of Charging for Respite Care	15
• Rural Issues	16
• Messages for Local and Scottish Government	18
• Other Relevant Comments	22
Appendix 1	25
Appendix 2	27

Marj Donaldson

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SUMMARY

This consultation was carried out with 21 carers living in rural areas who have volunteered to talk on the phone, or to respond by email to a series of consultations from time to time, over a period of about 18 months.

The aims were to make it as easy as possible for people in rural areas to take part and to ensure that the views and experience of carers in rural parts of Highland reach the people, both at local and national level, who make decisions about meeting carers' needs.

This is funded by the Scottish Health Council with a Community Facilitator contracted by the Coalition of Carers in Scotland and supported by Highland Community Care Forum.

6 of the carers are men, 15 are women.

8 care for children, 13 for adults.

15 have had experience of at least a small amount of respite, although this was not current for some.

In Highland there is financial assessment for charges for respite care for adults. Recently there was a suggestion that charges might be introduced for respite care for children on a means tested basis.

Of the ten carers of adults who had used respite services in the previous 18 months only one was currently paying. Two others had recently given up using respite care services, as a result of charges being introduced. The others had not been charged, receiving their respite services through a voluntary organisation, such as a local day care centre or Crossroads Care Attendants.

The Value of Respite Care

Appropriate good quality respite is highly valued by carers for many different reasons, such as rest and relaxation, opportunities to do 'normal things', different things or essential things not otherwise easily done. To some it was seen as a lifeline or a liberation, or both. For others a chance to devote more attention to other members was a very important aspect.

There were difficulties also - the feelings of guilt, the stress of all the organisation that goes into arranging for other people to take over and anxieties about the quality of the care that will be provided.

Charging for Respite Care

More than 80% of the group were against charging for respite care, some quoting the £8 billion per year that it is calculated carers save the state, others seeing it as essential in maintaining carers ability to continue caring and several spoke out against the *'intrusive and demeaning'* process of means testing.

Three people had given up or reduced their use of the service as a result of charging, and others felt that they, and many other carers would do so if charging was introduced for children's respite care.

Rural Issues

The main issues specific to rural areas were thought to be the lack of choice in the provision of services, the distances to services, and the resulting extra financial costs as well as time costs - *'travel time eats into your respite time'*. There was also concern about the staffing of care services, there being fewer people to apply for posts, and care agencies being unable to meet need.

Messages for Local and Central Government

These were wide ranging but principally related to the need for an adequate supply of services to enable people to continue caring, the need for high quality respite care and pleas for respite care to be free. There were also many positive and appropriate suggestions for service development.

In conclusion

It is clear that when the system works well respite care is of huge value to carers and is important to society and the state as it is a major factor in ensuring carers' continuing ability to care.

Key messages from this group are:

- that carers should not be charged for respite care
- that quality is vital for a real sense of 'respite' to be possible
- that ways need to be found of providing reliable care services in rural areas.

INTRODUCTION

The Coalition for Carers in Scotland (CoCiS) was granted funding from the Scottish Health Council to appoint Community Facilitators in rural areas of Scotland, who would engage carers in rural communities in influencing the development of health and social care services in their local areas, and in contributing to the national picture on the impact of national policy.

CoCiS selected Highland as one of the areas where such a scheme would operate, partly because of the support which could be offered to the Community Facilitator through Highland Community Care Forum (HCCF).

The remit for this project was

a) to ensure that the views & experience of carers in rural parts of Highland reach the people, both at local and national level, who make decisions about meeting carers' needs

b) to make it as easy as possible for rural carers to take part in contributing their points of view

The first round of consultation took place at the end of 2008 and looked at the financial impact of caring in a rural area. (see previous report)

'Paying for respite care' was a 'hot topic' by early 2009 in Highland as the Housing and Social Work Committee had put charging for children's respite care on the agenda for their January meeting. However at the last minute this was withdrawn as 'not enough work had been done on it' and 'in order to allow time for consultation'.

Some years earlier charges had been introduced for respite care for adults.

There are currently twenty-one carers in the consultation group and all responded to this consultation.

Those who agreed to become involved live in places well distributed across Highland. Five live in small country towns, seven in villages and the others are many miles from the nearest settlement. There are six men and fifteen women.

The profile of the group is as follows:

Caring for an elderly parent	4
Caring for an adult son/daughter	3
Caring for a school-age son/daughter	8
Caring for a partner	6

Of those caring for school-age children, three are also caring for an adult in the household, either wife or parent.

Six carers had not used respite services, two because they felt they were 'not yet at that stage'. The others had less positive reasons, reported later.

Two had been given Direct Payments with which to take on care workers directly themselves.

All participants were telephoned initially prior to the first consultation, so that the project worker could introduce herself, explain the aims and the format of the work and to find out if the carers would prefer to be involved by email or by telephone. On this occasion those who had provided email addresses were contacted in that way and given the choice of method. The others were sent a letter introducing the topic and then telephoned shortly afterwards to arrange a time for the more detailed discussion. The outcome was that twelve people contributed through a telephone conversation and the remaining nine responded by email.

On this occasion one of the carers in the group took the subject to a meeting of their local Community Care Forum where it was discussed by a group of people in the Gairloch area made up of carers, ex-carers, staff and ex-staff of care agencies. See appendix 1.

We defined respite care as 'temporary care arranged through Social Work Services for the person you care for, to give you some 'time off' from your caring role'. It was explained that the service, although arranged through Social Work Services might be provided by a different agency and that it might sometimes be referred to as a 'short break' rather than respite care.

The provision of respite varied, ranging from two hours per fortnight of a support worker's time to several weeks per year in residential care. It included:

A support worker who accompanied child to activities
Crossroads Care Attendants who came for 3 hours
Carers who came in for an overnight stay
A week's residence in a care home
Day care in the Hospice
Attendance at a local day care facility
Visits to a children's respite centre

None of the parent carers were paying for care and of the ten carers of adults who had used respite services in the previous 18 months only one was currently paying. Two others had recently given up using respite care services, one because of the cost and the other because the quality of the premises and the experience did not justify the price. The charges quoted by these three people ranged from £650 to £80.50 per week. The remainder were receiving their respite services through a voluntary organisation, such as day care centre or Crossroads Care Attendants, and so there was no charge.

People were asked to give their views on:

- The value of respite care for the carer(s) and for the cared-for person
- The impact that charging had had on their use of the service, or would do, if it was introduced for children's respite
- Any issues that are specific to rural areas in relation to respite care and its costs
- Points that carers would particularly like to make to Local and Scottish Government
- Any other relevant points

WHAT THE CARERS SAID

The Value of Respite Care

The high value placed on respite care was very clear in the language that people used when talking about it, such as '*fantastic*', '*very important*', '*hugely beneficial*', '*something to look forward to*'.

Value to the Carer

The main reasons for valuing it so highly were:

To provide a **rest** from a demanding lifestyle and a change from a limiting situation:

'I can get a whole night's sleep.'

'We often try to use the respite weekend to go away and stay in a hotel to relax & recharge our batteries for the next few weeks until respite again. We can only manage this two or three times per year so it is vital to have something to look forward to.'

Or it may be the **opportunity to do different things**, things that are not usually possible due to caring:

'I can visit friends and family - otherwise I would feel very isolated.'

'I go and have a cup of coffee with a friend.'

'It means I can catch up on essential things in life like doing the food shopping and paying the bills which I can't do when my son is with me.'

Others talked about it being an **opportunity for some kind of personal development**, eg, attending a child-care course, learning to swim or going to Open University summer schools.

It was striking the number of people who talked of respite as **a time to do what they perceived as 'normal things'**, demonstrating that otherwise they feel 'normal life' beyond their reach.

Another phrase used by a few people was about **the 'liberation'** that came with time off and that this was really something to look forward to.

For many parent-carers one of the main stresses of caring is the lack of **attention they are able to give to other members of the family**. If the cared-for child is away on a short break there is time for the rest of the family to relax together and for other children to get the undivided attention of their parent(s):

'When C is away, we'll have friends to stay and it will be easier for all of us - more normal.'

'My other son gets peace and quiet - and attention from his mother. I think he is quite deprived by his brother's condition.'

'It's great for our other children to get more attention from us and for them to be able to do the things they want to do without interruption from their brother. They can be themselves for a while.'

'Brothers can do the things they choose rather than what C chooses'
(italics)

And in several responses there is the sense of **the lifeline that respite breaks are**:

'I would go under otherwise'

'It's important for recharging your batteries, helps you avoid blowing up. It gives you a chance to find yourself again.'

'It prevents depression and resentment, both of which can be crippling. It dissipates tension, helps you to see the way out of the black hole - it's good to get a bit of distance.'

'It eases the strain on our relationship.'

'I have to fight to live a life of my own.'

'The benefit to me of using respite is incalculable. Aside from shopping trips and occasional afternoons with friends, I spend every waking hour caring for my partner. Her condition has deteriorated to the point where we cannot socialise and so I effectively have no life other than caring. I think that if I was not able to look forward to regular respite breaks I would become depressed to the point of not wanting to carry on, or

worse. As it is life is very difficult, and respite makes it bearable - just.'

Several people mentioned the importance of **trust** in the respite care services without which the short break could become more of a stress than it was worth

'We usually went away - great to have a trusted service.'

'It was liberating cos I trusted the place, and was so pleased he liked it - it meant I got full benefit of the break because I had no worries about him.'

The Value To The Cared-For Person

'W gets new experiences and meets other people.'

'Dad loved it, looked well and alert - he got a big boost to his morale, having comrades to talk to about shared past experiences.'

'C feels more normal, doing things that others do'

'It's great for our son to have a 'life of his own.'

Difficult Aspects of Respite Care

There were of course disadvantages too.

There were the feelings of **guilt** about being able to go away, about that feeling of liberation and the need to be away for a while:

'the guilt is hard enough to bear - the guilt about taking time out and feeling free of the responsibility for a short while'

There's also the **stress** of getting away and planning/organising all the arrangements for someone else to take over.

And there are worries about the **quality** of the care provided:

'It is stressful getting away and also wondering how things are going at home with carers - about the quality of the carers.'

'The quality of the service was so erratic and poor that it was more disruptive than beneficial.'

'My husband found the care home residents very 'cliquey'. I won't go away again because he didn't like it..

'Increasingly, she comes home with problems originating in the care home. Last time but one it was a huge pressure sore, shingles and a blocked catheter. Last time it was MRSA. For these reasons I would prefer not to send C to respite, but I simply cannot manage without a break.'

'And sometimes items of clothing go missing at the care establishment'

Carers with No Experience of Respite Service

Those who had no experience of respite services were, asked the reasons for this. Apart from the two people who felt that they did not yet require respite, there were the following explanations:

One carer had 'never been offered, nor received any, respite care for L. Chance would be a fine thing!'

Two people were basing their decision on negative experiences. One preferred to take her children to other members of her family as she had found little understanding or appropriate provision for her autistic son at the nursery he had attended.

'I am wary now of him going anywhere else like that because he was not given the support he needed, for example when the other children hurt him by calling him names. I would need to be able to trust that they understood, and would cater for, his condition.'

The other person found that

'Social Services make you jump through too many hoops. Exhaustion was always on the agenda anyway and the stress of dealing with forms and inquisitions would not encourage me to go down that route. If part payment is required that complicates any application, so more stress and investigation. It all begins to seem like a device to put you off, rather than a hand stretched out to help in an extremely difficult situation.'

The remaining person had been assessed as requiring respite care but

'Our experiences have shown that the needs of our family have always been inconsequential with regards the actual provision offered. Our only experience of residential respite was marked by the filling in of forms just in time for social services to be able to put down on a report that our needs for this service were being met.....and funnily enough we have subsequently experienced not one single night of respite in 7 years.'

Charging for Respite Care

The majority (but not all) of the group were very against the idea of charging for respite care for adults or children and made this clear in no uncertain terms. There were four main reasons for this:

Saving the state money

'I feel that every carer should be entitled to a certain amount of respite care, with no charge, annually. Often carers have already had to reduce their working hours to accommodate their loved one which means financially they are already out of pocket. This would be a cheaper option than having their loved ones in care.'

'I looked after my dad for almost three years. I took £180 a month from him. He is now in a care home and they take £1800 a month so surely if this is what most cases are like, it should be worth giving an amount of respite care and allowing carers to keep their loved one at home for longer.'

'It should be free for all. I'm pleased to get it and willing to pay, but feel I shouldn't have to because of the job I am doing and the money I am saving the state.'

'Scotland's population of carers are calculated to save the state some £8 billion per year, while the Carers' Allowance is the lowest throughout the benefit system. '

'I can see there could be an argument to say if we can afford to contribute, eg, if we have more than £6000 in savings (which is the most we can have on benefits and chance would be a fine thing too!) we could do so to some extent. However, on reviewing all that goes into the caring role and how little one is paid for carrying out this extremely stressful role, it would disadvantage the carer mentally and physically if the stress of payment were added to this supposedly stress free time of respite

from the caring role. The service should be offered with as little red tape as possible, otherwise people just will not use it, and cynical as this may sound, I believe that is exactly why difficulties are set in the way: to deter.'

'It's a nonsense - there should be enough for all to get free respite. '

Enabling Carers to Continue Caring

'Government and social services would be shooting themselves in the foot asking for payment putting more difficulties and strain the way. Carers do a magnificent job which is hardly rewarded enough, without extracting more payment, so a definite NO from me to paying for respite care. The value of carers is widely known and accepted, as they save the economy a great deal in the cost of care so they should be valued and respected and not made to pay for a respite from caring.'

'There is an argument for saying that respite should be provided as a resource to enable carers to continue in their role, and not as a service to be charged for - the cost of a carer having to give up is many times higher than would be the provision of an adequate respite programme'.

'Definitely should not have to pay. It's very important for maintaining the carers' ability to care at home and no child should have to leave home.'

'The whole family is affected and needs support and breaks.'

'There could be a big backlash with people giving up caring and children having to go into care, or parents cracking up.'

'Carers are doing an important job and should be supported by society'

Frustration

'It's atrocious that carers should be charged for short breaks - we should not be penalised for having/caring for a disabled child.'

'absolutely not - carers deserve their respite - they don't get much else - it's the least that could be offered'

Financial Assessment

Some people, from their previous working or caring experience had strong views about means testing and financial assessment:

'Means tests are never fair - those at the threshold always suffer'

'I personally hate the financial assessment process. It is intrusive and demeaning - makes you feel guilty for having any savings. And I am sure I'm not alone in thinking that the assessment formula seems rooted in the dark ages. I resent the fact that highly paid council executives decide how much (how little) we are supposed to be able to manage on after the charges are taken. They would not dream of trying to survive on so little but it's all right for 'us'.

'People are fearful and frustrated by the financial assessment form - it's very daunting. People need moral support to fill it in - it requires a knowledge of the system and what is being looked for.'

In favour of Means Testing

There were four people who felt that charging for respite care for those who could afford it was not unreasonable, so long as the threshold was set high enough and people's individual outgoings were taken into account:

'I think that most carers would acknowledge that a contribution to the costs of providing short breaks would be reasonable. The most important issue is that the cost should not create a barrier to carers accessing a break.'

'Means testing is acceptable if the threshold is high and outgoings are individually considered, eg, the extra transport costs of living in a rural area, and the extra heating costs that carers often have.'

'Care should be means tested - then those who most need it might get it.'

'I think it should be means tested. The problem with anything being free to all is that the service will end up smaller.'

Several people, while not necessarily believing that care should be charged for, said that they would pay anyway, because the benefit of respite was so vital.

The Impact of Charging for Respite Care

Reducing Use of the Service

Three people who took part had reduced or given up using respite services when charges were introduced, and others anticipated that they, and others, would do so if charges were introduced for children.

'We had respite booked, but when charges were introduced we cancelled it and have not used it since - our accountant said it was too expensive.'

'People will choose not to take it - and then realise what a mistake that was.'

'Carers are always having to budget and they won't necessarily prioritise respite.'

'The impact of charging was initially quite serious. Lacking any income aside from savings and the pathetic Carers Allowance, I had to make some difficult decisions to ration my use of respite and in fact have never used my full allowance.'

'There's a real danger in people not using the service cos they think they can't afford it.'

'Charging clearly adds a barrier to carers use of respite services, and this barrier can manifest in different ways. Some carers (sometimes through insufficient knowledge of the system) will anticipate that they cannot afford the services, so will not ask. Others will be so desperate for a break that they will seek opportunities irrespective of cost and ability to pay.'

'Respite is essential. People don't ask to be ill, so don't add to the pressure by charging for respite.'

'The introduction of financial charges for my daughter using respite care would be catastrophic, we would immediately hit financial hardship because I presume the cost would be very expensive. We could not afford to pay for respite care, which would severely affect our home life and that of our daughter and her siblings.'

Quality

The introduction of charges highlights the issue of quality of care - people are not so likely to accept poor quality when they have to pay for the service.

'Charging would change your whole way of looking at the service - it would need to be good.'

'Quality would be a more important factor when deciding whether to use respite or not - I would happily pay if it was good and consistent and I could trust it to last, so important with autism.'

'We wouldn't use this service if there was a charge as there would be better ways of using the money (the service is not that suitable - it would be better if a social worker would accompany C to his clubs rather than the others in the family having always to do what C wants to do - if the support worker came at a better time, the other boys could do, with me, things of their own choice.'

Two of the carers, one using Direct Payments and one whose financial assessment means they are charged the full amount for respite care have chosen to go on group activity holidays as an alternative to respite care.

Rural Issues

The carers saw three particular aspects of rural life having an impact on respite.

Lack of choice

Several people mentioned that there were *'so few choices of provision'* of respite care, one person whose experience of respite in a local care home had not been satisfactory for her husband, made the additional point *'if you lived in the city you would be able to visit different respite providers and choose the one that best suited.'*

Another said *'if we lived in a town, within reach of activities for children, the other children in the family would be able to do things independently. They wouldn't all have to stay together on account of their autistic brother.'*

Transport - time and costs

The lack of choice in a local area leads people to travel longer distances to respite care or to activities and this in turn leads to greater costs.

'The main issues which are specific to rural carers are probably the reduced choice of respite homes, and the time and cost taken to access respite services. The lack of interest shown by Social Work in providing better choice, especially for younger people, means we are being forced to go further and further afield to find suitable respite care. Currently this involves a 80-100 mile round trip, which is time consuming, costly, and is far from ideal for someone in a wheelchair who is chronically sick.'

'Huge distances to be travelled to the respite of our choice'

'We were offered a playscheme place but it involves two hours transport time and that's very difficult for our son.'

'Travel time eats into your respite time.'

'Carers particularly in rural areas, suffer from overall financial effects of caring, with lower incomes and higher costs'

'Transport is a problem - the distance to one centre is 130 miles round trip taking 2 - 3 hours, or 110 to the other, taking 3 - 4 hours due to road layout, tourist season etc. Therefore you immediately have a cost in fuel, wear and tear.'

Staffing issues

Carers were very conscious of care agency staff shortages in rural areas, perceiving that where population is sparse, there are fewer people to apply for the jobs, and that the quality may suffer as a result.

'I think that the services would be better in the city - staff would be better trained and supported.'

'Knowing that there are no carers available in the area I don't like to burden them with requests for respite as I know how hard pressed they are as it is.'

'There are not many people from whom carers can be selected.'

'Needing to be a driver further restricts the number of carers who can be asked to come all the way up this glen.'

'People don't apply/refer because they know there is no-one to supply the respite care, so the unmet need is not catered for or recorded.'

'We can't get carers in our area so no home respite available.'

The two families who were using Direct Payments also experienced this problem. While they were able and willing to organise and train their own care workers, they found it impossible to find people willing to take on the work, on a long term basis.

Other

Another disadvantage of rural life was highlighted by one carer:

'You can't advertise locally for a support worker because it would be instantly known who the support was for and other children would taunt C.'

'Everyone knows everyone, so no chance of an alternative social life. Its hard to break out of any preconceived ideas (DS) which build up in people's minds around a child with autism.'

On the other hand:

'What happens now is better - W helps out on local crofts and if I'm going away for the day he gets his lunch there and can microwave something for himself in the evening'.

And another was keen to point out that

'We always felt we were being treated equally to those who live in the city.'

Messages for Local and Scottish Government

Carers' messages for the authorities were many and, not surprisingly, covered a broad range but could be grouped as follows:

Supply of services to enable people to continue caring

'Respite is essential - it's so important to look after yourself so you can look after others. They need to look at the bigger picture - if people don't take/get respite their ability to care long term will be affected. '

'Carers have to have time off - you have to avoid swamping them. Concentrate on helping carers to carry on caring.'

'At least one free week should be guaranteed for all - and more would be better.'

'Respite care should be adequately resourced and readily available.'

'Respite helps to keep carers caring, so it saves on the bigger expenses there would be providing the service in other ways.'

'You have to understand the importance of knowing respite is available even if you don't make use of it.'

'Carers earn their respite - they don't get much else. It's the least that could be offered.'

'Rural services don't get the resources/support/understanding that they need.'

Quality

'Respite is a fantastic experience when it works well - huge efforts should be made to make it work for all'

'When respite is offered it must be of trustable quality.'

'The charges for respite care take no account of the quality of the care provided, and Social Work seem little interested in whether the experience is a good one. Carers have to pay even if the care home is poor and there is no apparent mechanism for commencing payment if there are problems with the service or if, as regularly happens, the care home loses items of clothing etc. This is a very unsatisfactory arrangement - if, for example, a hotel lost your clothes you would reasonably expect some form of compensation, but this does not exist for respite care users.'

'Quality should be better.'

'Quality and choice should be available.'

'Service should always be provided by Council because you can trust their standards - not so with profit driven private companies.'

'Staff need to be properly trained and properly managed/monitored.'

Charging for Respite

'I still resent the fact that the government gives carers like myself a paltry £50.50 per week Carers Allowance, then taxes this, and then we are supposed to pay for much needed respite care - at a higher rate than the Carers Allowance. Then, if there is anything left over, we can pay for the break which we need. It is no wonder many carers do not use their full respite allowance. We are being taken hugely for granted and all the charges work against us in a way which is most unfair.'

'I would like to ask Highland Council why they feel it is important to charge carers for respite care, given how much we save the community by doing what we do. The charge may only be a small proportion of the true cost but it can be a significant cost for some carers. It is surely counter-productive to create a situation where carers reduce their take-up of respite due to these charges, and thereby increase the risk that they will be forced to abandon their caring role.'

'Any charges will alienate carer's, result in reduced usage of respite facilities, increase the NHS Budget because carers will require more medical help than before, including usage of Anti-Depressants and stress counsellors, doctors' time. You may also find some cases of resentment because of the financial implications caused by the charging. Financially the whole system of charging will bring carer's to their knees.'

'The government and many studies have all proven that carer's save the British Government billions of pounds per year by providing care at what would be considered slave labour rates. Therefore the introduction of charges should also see the introduction of proper payments for caring. The Carers Allowance should be increased to reflect the role carer's play in society and perhaps having a proper salary for caring may mean that any financial charges could be met and paid for. A proper payment would be in the region of at least £20-30.00 per hour when you consider that

carers are on call up to 168 hours per week. Currently the Carers' allowance payment amounts to a paltry £0.30pence per hour. I also believe that any proper payment should also be tax exempt to reflect the amount of work involved. Most if not all carers exceed the EU working Time Directive and if it was applied the government could not afford financially to meet the costs once the carer stops work.

But we all know the government knows that us carers will work until we drop or die

I also believe that if charges are going to be introduced then DLA caring payments should rise to meet these additional costs or an alternative method would be to have the caring element paid direct to the respite facility similar to the motobility scheme.

I will resist paying for any respite service for my daughter until she becomes an adult because the idea of charging is fundamentally flawed, when you consider the government is encouraging and offering free nursery school places and free after-schools clubs in some areas. These disabled children are then being potentially having their human rights denied by the introduction of charges.'

'If paying is on the agenda, people simply will not take up respite care as psychologically it will feel wrong, not to mention increase pressure and hardship.'

'Alienation is a real key factor (if charges are introduced) as I believe carers will just fade away, continue providing care to the person they care for and disappear into the ether until either the stress results in accidents or the carer actually becomes too ill to look after the person. Resulting in the carer having to be cared for and the person they used to care for going permanently into a home'.

Suggestions for service provision

'Respite care in our own home would be good and should be on offer - especially important for my husband because of his partial sight

'Improve co-ordination of respite services - they should have a respite team'

'Positive Partners is (DS) a good scheme - everyone benefits - not enough of them - recruit more - can build up a relationship'

'Crossroads should have a contract to provide respite care, so that they are not dependent on fund-raising - and the quality of care they provide is so good.'

'The best quality of life is in your own home in your own community, therefore everything possible should be done to enable this - (paid) carers need higher wages and higher status.'

'Raise the status of caring jobs - make caring a more attractive job - better conditions,(DS) more pay, value the carers more, recruit more, praise them more.'

'Reward good work, retain more, monitor more.'

'Everything in Social Work and Health is too bureaucratic these days.'

'Monitor the use of Direct Payments - not everyone is using the money they have been allocated. This could be re-distributed to pay for services badly needed by others.'

Other

'the Scottish Government is very centrally focussed - rhetoric comes first - not grounded in reality'

'I think access to information about respite services is patchy or not fully promoted, I have been to meetings where other carer's seem to get a poor service compared to my own. I think if you have a committed social worker then things move better, than a social worker who is apathetic to your needs, I can personally confirm I have had both types with the apathetic version actually increasing my stress levels.'

Other Relevant Comments

The other comments also unsurprisingly were diverse but can be grouped under the following headings:

Suggestions for service development

'The Circle of Friends in school has been very helpful - an idea that could benefit others.'

'Family care would be good, eg, using B&B places in the off-season - with visits from Health Visitor to check on care - we wouldn't have to travel far and it would provide local winter income for B&B people.'

'Need for youth club for young people with special needs - not available in rural area, and no support worker for evening activities.'

'Maybe with training and support more families could offer respite opportunities for their relatives or friends.'

'When you go onto Direct Payments you need support to get started - and to call on when things don't work out. The way it is just now means I have to carry all the guilt and stress myself then.'

Negative comments

'Choice is very limited, particularly since Social Work introduced its block booking system and chose a totally unsuitable care home for its younger adults provision.'

'They don't guarantee your place when you've booked respite, which is not good for confidence when making plans to go away.'

'We had to book a long way ahead and still didn't always get slot we wanted.'

'The service we get isn't really suitable for what we need. Better tailoring would be appreciated.'

'Social workers very hard pressed - not able to offer quality service.'

'No-one in Social Work ever sat down and explained respite options.'

'Social Work Services have a constant turnover of staff - this is no good, especially for someone with Alzheimers'

'Everything too bureaucratic now in Health and Social Work'

'The system of Direct Payments is all very well, but no-one tells you how to get the best use of them, about the services you can buy etc'

'Social Work Services shunt you off onto Direct Payments because they can't get the carers either.'

Positive comments

'Well trained workers at Crossroads - if I could get 3 days away with the 2 carers I know - I'd be willing to go to the moon I trust them so much.'

Crossroads excellent

'CPN excellent - came every 3 weeks for three and a half years - was supportive, gave tips and was consistent'

'Excellent service at Thor and the Orchard'

Miscellaneous

'It's Unfair that your savings for son's future are counted in the means test.'

'Matching of carers would be wonderful, eg, young male support worker for outdoor activities.'

'Health and Safety hinders common sense and natural human kindness'

'Social Workers currently have to deal with too wide a range of people and needs - should be more specialised. If attached to health centres they would have good local knowledge and not have to spend so much working time driving'

'Respite needs to be for a reasonable amount of time cos you need time to get used your child not being there.'

"I worry about how other children are affected, eg, don't get enough attention, younger child mimicking older autistic brother.'

'There will be other reasons why respite services are not used - there may simply not be respite available at a suitable location, carers may be unaware of the availability of services, or be unwilling to seek them because of a previous bad experience - though I would suggest (on the basis of my own experience) that this need not be a factor, given a positive approach to problems on the part of all involved.'

In Conclusion

It is clear that when the system works well respite care is of huge value to carers and is important to society and the State as it is a major factor in ensuring carers continuing ability to care.

Key messages from this group are:

- That respite care is crucial in maintaining ability to care
- that carers should not be charged for respite care
- that quality is vital for a real sense of 'respite' to be possible
- that ways need to be found of providing reliable care services in rural areas

APPENDIX 1

GAIRLOCH AND DISTRICT COMMUNITY CARE FORUM SUMMARY OF DISCUSSION ON RESPITE CHARGING: 23 MARCH 2009

Introduction

The following summarises views expressed by members of the Forum at their regular meeting. The group comprised ten people and included carers, ex-carers, community volunteers, retired community workers and care providers, and paid workers within the voluntary sector.

The purposes and benefits of respite care

To provide a break in a changed environment which can help coping when carer and cared-for are back in their home environment.

To have something to look forward to.

It should not be forgotten that there are barriers against carers seeking respite - stress and guilt are challenges, made even more difficult when ill children are involved.

The experience of respite - even only very short breaks of two or three hours - was positive. "I felt so much better for it!"

Views about whether or not households should be charged for respite care

The overall view was that some form of contribution was reasonable, particularly if the service was being provided by a charity; but it must be based on the ability to pay. However, where children's respite was concerned, there was much more hostility towards the concept of charging.

There was general agreement that the question of charging should be entirely dependant on individual circumstances, and that the additional cost to the provider of intense levels of care should be built into the equation.

Any contribution should be limited, and the contrast was drawn between the low level of the Carers' Allowance, the amount saved to the public purse by unpaid carers, and the cost of respite services where charges applied.

Differences made by charging to use of respite services

Charging clearly adds a barrier to carers' use of respite services, and this barrier can manifest in different ways. Some carers (sometimes through insufficient knowledge of the system) will anticipate that they cannot afford the services, so will not ask. Others will be so desperate for a break that they will seek opportunities irrespective of cost and ability to pay.

It was clear that serious confusion exists over charging systems, and this confusion must be attacked.

'Respite is essential. People don't ask to be ill, so don't add to the pressure that's already there!'

Issues associated with charging for respite care that are specific to rural areas, or heightened because of living in a rural area

All help in rural areas is at a disadvantage, and has to be fought for.

Resources are difficult - especially at holiday times.

There will be either increased cost or decreased hours in remote areas.

Possible comments to Highland Council and to the Scottish Government about charging for respite services

Respite provided by a state agency should only be charged for as a last resort, and only if the individual concerned can afford to pay.

The cost of any care package replaced by a respite break should be deducted from the cost of the respite.

APPENDIX 2

Cross Party Working Group on Carers

Charging Carers for Services - Briefing Paper April 2009

Current practice regarding charging carers for services

Local authorities do not have a duty to charge for non-residential care services. Instead they have a discretionary power deriving from section 87 of the Social Work (Scotland) Act. This empowers a local authority to charge the person who 'avails themselves of a service'. If a local authority chooses to levy a charge, it must not require the service user to pay more than they can reasonably afford.

COSLA guidance on charging policies for non-residential services (2006) states:

"Only the person receiving the service is expected to pay charges directly although it is left to the local authority to decide whether a client has reliable access to other resources such as those of a partner."

Local authorities have chosen to interpret this guidance in different ways. As a consequence, some carers looking after a partner or spouse have had their income taken into account during the financial assessment of the person they care for. Worryingly, some local authorities are now considering, or beginning to consider, assessing the income of parent carers when considering what services to provide to disabled children aged 18 or under.

Policy and Context

We believe that COSLA's guidance runs contrary to the spirit of regarding carers as 'key partners in the provision of care', a principle given statutory recognition in the Community Care and Health Act 2002.

The Community Care and Health Act 2002, New Statutory Rights for Carers, Guidance states:

"Where a carer and cared-for person are related in a way that means their household income is considered to be joint, any charges levied on the cared for person would also directly effect the carer, which would be contrary to the Executive's policy that carers should not be adversely effected as a result of their caring role."

It also runs contrary to the principle established in the Repeal of Liability of Relatives Act 2007 which states:

"Where a person's accommodation is provided at the public expense by a local authority, the local authority cannot ask the spouse (i.e. the liable relative) to refund all or part of that expenditure."

National Carer Organisations Position on Charging

The national carer organisations believe that carers should not be charged for services received by the person they care for. We recognise that carers already save local authorities substantial sums. Recent research¹ found that the cost of replacing care provided by carers would cost the Scottish economy £7.6 billion each year.

¹ Valuing Carers, Carers UK, 2007