



Submission to the consultation on Regulations and Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

We write on behalf of the Coalition of Carers in Scotland in response to the consultation on the Regulations and Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

1. Information on the Coalition of Carers in Scotland

1.1 The Coalition was established in 1998 and represents over 80 local carer organisations. Through our members we reach and inform over 60,000 carers in Scotland.

2. Background Information

2.1 There are over 660,000 unpaid carers in Scotland¹ who save the government £10.3 billion pounds every year, equivalent to more than three quarters of the entire budget of NHS Scotland². Of these, 115,000 care full time, without pay, for over 50 hours a week – roughly equivalent to Scotland's total paid care workforce³. With our increasingly ageing population, the number of unpaid carers is set to grow, with society becoming ever more dependent on their contribution to health and social care delivery.

2.2 With the current move towards shifting the balance of care to care at home, family members, relatives and friends will play an increasingly central role in the care and treatment of people who are frail or live with long term conditions, illnesses and disabilities. Unpaid carers are the primary providers of personal and social care in Scotland, with more unpaid carers providing support than the entire health and social care workforce combined.

2.3 The implementation of the Social Care (Self-directed Support) (Scotland) Act will result in a significant shift in the delivery of health and social care services. For this to be successful, carers must be involved as equal partners in care, both in the design and delivery of outcome focused support for the people they care for and also as recipients of SDS themselves.

3. Introduction

3.1 We support the move towards more personalised, self-directed support. Carers and the people they care for welcome the opportunity to exercise more choice and control over the services they use.

¹ Scottish Household Survey 2007/2008

² Valuing Carers, Carers UK. 2011

³ Census 2001

3.2 Until now, implementation has been variable and not all areas have upheld the underpinning principle of personalisation when re-designing their services to incorporate self-directed support. It is our hope that the Social Care (Self-directed Support) (Scotland) Act 2013 and the regulations and guidance which accompany it will be robust enough to ensure the equitable and successful delivery of self-directed support across Scotland, translating the vision of personalisation into reality.

4. How we consulted with carers and developed our submission

4.1 As part of the National Carer Organisations Group (NCO) we developed a briefing paper on the draft guidance and regulations which was distributed widely to carers and other stakeholders. This outlined the key aspects of the Guidance and Regulations relating to carers and explained how people could contribute to the consultation

4.2 In addition, the NCO facilitated consultation sessions at both national and local events, primarily with carers, but also with practitioners working with carers. People have had the opportunity to contribute their views via an online survey and through a Webinar session. Over 300 people contributed to the consultation. Their views have informed our response and have also been captured in a report, which is included as an Appendix.

4.3 The Coalition has also contributed to the joint submission from the National Carer Organisations Group. As well as highlighting some of the key issues for carers, the NCO response goes into more depth in relation to the detail and wording of the regulations and guidance,

4.4 This response aims to highlight those issues which carers and other stakeholders have identified as being of particular concern and where possible to provide recommendations in relation to addressing these concerns.

5. Draft Directions (The Carer's Assessment (Scotland))

5.1 We welcome the addition of directions to local authorities in relation to carers assessments and the interpretation of 'substantial and regular' We hope that this will lead greater consistency across Scotland and a more preventative approach to promoting and undertaking carers assessment.

5.2 At the moment the number of carers assessments being undertaken in Scotland varies greatly. According to figures from an FOI request in 2012, of the 18 local authorities who responded providing information on the number of carers assessments carried out in 2010/11, eight undertook less than 100 assessments, with three carrying out less than 50 and one only providing eight assessments to carers. While some areas have seen a marked increase in the number of carers assessments in the last few years, others are falling far behind.

5.3 We are hopeful that the regulations, in providing a more holistic approach to the interpretation of 'substantial and regular' will allow a greater number of carers to access an assessment. However, we feel that the quality of the assessment process and the outcomes it produces for carers is of primary importance and in order for the directions to achieve their goal, it is imperative that they are provided in context.

5.4 We recommend that the Directions should include an introduction explaining that carers are equal partners in care and should be assessed to determine if they require resources to support them in their caring role. This should reference the Community

Care and Health (Scotland) Act Carers Guidance, placing the definition of 'substantial and regular' in the context of resourcing carers to continue to care '**as much and as long as they wish and feel able**':

3.2.1 The Executive's policy is that carers should be supported to allow them to continue to care as much and as long as they wish and feel able. The 2002 Act does not provide for services to carers. Carers, like other service providers, need resources to carry out their function. For carers, these resources may be in the form of other care services to help support the cared-for person, or support or advice provided directly to the carer.⁴

5.5 The Directions include a range of factors which should be taken into account in determining whether a carer provides 'substantial and regular' care and therefore should be entitled to a carers assessment. The last factor on the list is 'the carer's views'. We believe this should have more prominence and that the carer's views should be the first consideration when deciding if they are entitled to an assessment

5.6 The final point - 3.5.6 of the Directions makes reference to the value of carers assessments as a preventative approach and makes the point that early access to small interventions may prevent the subsequent need for increased levels of support and the breakdown of the caring relationship. We believe this is an important point that should receive more prominence and be included within an introduction.

6. Draft Carers (Waiving of Charges for Support) Regulations

6.1 We welcome the waiving of charges for carers. As equal partners in care the principle of carers as care providers who require resources to enable them to continue in their caring role is an important one and charging carers for services goes against this principle.

6.2 In our consultation, both carers and other stakeholders have overwhelmingly agreed with the principle of waiving charges, with 96% of respondents strongly agreeing or agreeing that carers should not be charged for the support they receive to help them in their caring role.

Carers are delivering a service, why should a person pay under these circumstances

This is fundamentally an issue of equality. Already carers make a range of sacrifices, including bearing financial costs, so to add to this would be very unjust and add to existing inequalities

6.3 We also welcome the inclusion of short breaks, including holidays breaks, within the directions. We are pleased that the cost of replacement care will not be passed on, enabling the carer to take a short break without the concern of this impacting on the finances of the person they care for.

⁴ Community Care and Health (Scotland) Act 2002. New Statutory Rights for Carers Guidance

Holiday Short Breaks

6.4 Carers have welcomed the proposals for local authorities to meet the full costs of a holiday short break where carers are assessed as needing one. Of the people who responded to our consultation 85% strongly agreed or agreed with this policy. Carers particularly welcomed the proposal that local authorities should fund the additional costs of a holiday relating to their caring role, such as replacement care costs, and any care related expenses. Comments included:

Several reasons to justify this: 1. Enabling families with a person with support needs to lead normal lives 2. The preventative factor of such breaks, with huge potential to strengthen relationships 3. A cost-benefit analysis would show the huge savings to NHS/LAs from the unpaid caring relationship which in purely economic terms warrants this investment

No one should be excluded from the essential service because of financial circumstances

I have been on breaks with my disabled husband and had to pay through the nose for hire of equipment and carers but it allowed us to have a 'normal' holiday What a difference it made

We had a break away last year where the cost of the cottage was paid for by the local authority but not the cost of two carers (needed for hoisting by their request) so it was not much of a break really as I had to be the second carer

6.5 However, concerns were expressed about the ability of local authorities to meet demand without additional resources. Several people thought that this is likely to result in the tightening of eligibility criteria with fewer carers able to access a break.

In an ideal world yes - but I understand financial constraints - so for me, I think respite costs need to be met for all before thinking about holidays for carers. There are also pots of money available through charities for holidays.

Local Authority can only afford to cover these costs if they were given the money by Government to help. It would not work if our local authority had to pay for this care via an already decreasing budget

Genuine partnership working with carers is essential. Carers aren't stupid - they know that there are not unlimited funds available - sharing openly and honestly with them the restrictions that have to be worked within would enable them to see how they could best use the resources available to them.

6.6 There are many existing schemes, such as short break voucher schemes and the Time to Live Fund which provide financial support for carers to take a short break, including a holiday. This best practice should be built on with an emphasis on promoting the best outcomes for carers and enabling choice. Priority should be given to funding carers who otherwise would be unable to afford to take a break.

Ideally I think it would be good if there could be a bursary or a grant towards a break but I think it is unrealistic to think the local authority could cover all the costs! A grant towards a break would be helpful as it is definitely more

expensive to go away on holiday with a person with a disability, especially if you need somewhere adapted

I'm not sure how they will assess what type of break is the right break? There should be a contribution to short break costs which carers could choose to top up if they want a more extravagant break

The Expectation that family and friends will provide replacement care

6.7 Carers have expressed concern about the wording of the regulations in relation to carers accessing a short break. They currently state that replacement care will be provided in circumstances where 'there is no one who will provide the replacement care free of charge to the person unless it is provided or arranged by the local authority.' The guidance states that in order for carers or young carers to have a break 'the expectation is that the replacement care will normally be provided by friends, relatives or neighbours' It then goes on to say that 'Only where other people such as friends, relatives, neighbours or indeed volunteers are not available to provide replacement care free of charge would the Scottish Government expect local authorities to provide or commission replacement care' It then cites 'social isolation' as an example of where this may apply.

6.8 We asked carers and other stakeholders if it was reasonable to expect carers to ask friends and family to step in and provide support before they ask the local authority for help. 29% agreed or strongly agreed with this and several people said the support they receive from family and friends is invaluable and is the preferred option of the people they care for. However, 61% of respondents disagreed or strongly disagreed and many cited reasons why it was not possible or desirable to ask friends and family to provide replacement care. Examples included:

- the specialist nature of care required, which family members and friends do not have the necessary skills to provide
- the challenging behavior of the cared for person
- the need for equipment and adaptations which are only available in the carer's own home, or which a person would require training to operate
- concerns about the health and safety of family members when providing care and what would happen if they injured themselves
- the reluctance of family members and friends to provide support
- concerns that asking for more support than was already provided would lead to resentment and existing support being withdrawn
- not being able to rely on this source of support, making it impossible to relax when having a break
- family members living too far away or being unavailable due to other commitments, such as childcare and employment
- concerns about the safety of vulnerable people without the appropriate checks and safeguards which are in place for paid workers

- being unable to afford to pay for the expenses of those providing replacement care, such as transport, meal costs and outings.

Responses included:

Carers should not be expected to beg for help from anyone

For some people, asking for help is an admission of failure. This would be worse if there was an expectation that they ask friends and family first

My daughter has complex needs, family and friends do not have the required skill level

This is a very difficult question, close family will help when asked. In my situation an easy way to lose friends

They will know the person, look how many people have a different carer every week or so

I already do this and sometimes pay them if the support is for a long period of time

My son would not want his elderly grandparents dealing with his personal care

I cannot ask my 30 yr old son to look after his sister because it is very inappropriate e.g toilet and washing needs, dressing etc.

I wouldn't dream of asking friends as I wouldn't have any left! As for family it can make a carer feel bad having to ask all the time as they feel they are beholden to that family member and it can cause awkwardness if they are told no when asked

Our child's behaviour is so violent that we don't blame family and friends for NEVER offering help. Sometimes it might be inappropriate anyway if they don't have disclosure

'Expect' is a very strong word. Individuals with a strong family network might be fortunate enough to be able to rely on their immediate family members for support. However, depending on the needs of the individual being cared for, it might in fact be unreasonable to assume that family members are comfortable in administering care/medication/support at the level required.

6.9 In most instances carers already receive support from family members and friends, where that is suitable and available. However, we do not believe there should be an 'expectation' from local authorities that carers must first ask others before seeking resources from them to help sustain their caring role. Local authorities should not be obliged to interfere in any voluntary care arrangements between carers and their families and friends. We also believe if this were to be implemented, it would not be enforceable and would be open to legal challenge.

6.10 The regulations also suggest that volunteers may play a role in providing replacement care. There are many good examples of carers receiving support through volunteers, such as befriending services which can provide a valued service to the cared-for person while enabling the carer to have a break. However, these services require resources to ensure volunteers are appropriately recruited, trained and

supported and this role needs to be undertaken by organisations with the relevant expertise, such as volunteer centres and carer support organisations.

Universal Services

6.11 Some local authorities have suggested to local carer organisations that SDS may be an income source in the future if carers choose to purchase such services via a direct payment. There are concerns that this will be viewed as an alternative form of funding to the present system. Services provided by carer support organisations are currently free and can be accessed without a formal assessment. They include information and advice, emotional and peer support, advocacy, counselling and training. Most carer organisations receive core funding from their local authority or health board in the form of a grant or service level agreement.

6.12 We believe that this would undermine the current provision, potentially leading to a two-tiered system where only carers in receipt of a direct payment, following a statutory carers assessment would be able to access certain services. As a result, early preventative support would be lost leading to crisis provision and more costly interventions being required.

6.13 This issue was raised with the Minister, Michael Mathieson MSP, in October 2012. He reassured the National Carer Organisations that the regulations would make it clear that SDS should not to be viewed as a funding source for universal carer services. However, the regulations are unclear on this point and confusingly do not differentiate between services which are currently free and therefore there is no charge to waive and those which generally have a charge, where the charge will be waived for carers.

6.14 Section 10 of the Guidance accompanying the Draft Carers Regulations lists the services for which charges will be waived for carers as:

- the provision of information and advice, including signposting to other agencies
- advocacy for carers and young carers
- emotional support and counselling
- training for carers and young carers
- translation and interpretation services
- support with housework or gardening or other similar activity
- cost of taxi fares and driving lessons in special circumstances
- short breaks

Many of the services listed do not currently incur a charge and therefore there is no charge to waive. It is confusing to include these in this section and they should be removed due to the potential for them to be mis-interpreted by local authorities.

6.15 We are also recommending that the example of carer support, included in the Draft Statutory Guidance should be removed:

The professional arranges for an individual service fund to be set up. They arrange for

*this to be transferred to a third sector organisation (say, a carer's centre). This organisation purchases training or peer support sessions under the direction of the carer.*⁵

6.16 We believe the regulations and guidance need to clearly differentiate between those services which a carer may choose to purchase with a direct payment in order to sustain them in their caring role, such as a short break, driving lessons, or practical help with housework and those services which a carer can currently access without an assessment or a direct payment.

7. Draft Statutory Guidance

Employment of Relatives

7.1 The broadening of guidelines in relation to the employment of relatives is welcomed. The current criteria of 'exceptional circumstances' has been interpreted widely across Scotland, leading to a lack of equity for carers and direct payment recipients.

7.2 MECOPP undertook a survey of local authorities and their current practice in relation to the employment of family members. Of the 13 areas that responded, the number of family members employed on a permanent basis, from April 2011, ranged from 0 to 37, with most local authorities reporting less than 10 family members employed through a direct payment. The way 'exceptional circumstances' is being defined by local authorities varies considerably, with responses such as:

(the local authority) take a person centred approach to employing relatives through direct payments and look at each case on an individual basis

Exceptional Circumstances are deemed to be circumstances where it has not been possible to make other appropriate arrangements for support. Paid family support is deemed to be the only way of fully meeting the individual's needs. Where it is possible to find an appropriate alternative to paid family support we would not agree to the use of direct payments to employ a family member. We don't permit legal guardians and attorneys to employ themselves to provide the paid support.

7.3 We are hopeful that the guidance will encourage more local authorities to agree to family members being employed where this is the right option for the direct payment recipient and the family member. To ensure that implementation is fair and equitable we recommend that local authorities should have a duty to inform direct payment recipients of this option, as well as a duty to reply in writing to every request from direct payment recipients who wish to employ a family member. Where the request is refused they should explain their reasons and offer the right to appeal the decision. Of the 13 local authorities who responded to MECOPP's survey 58% had a policy in place for the employment of family members, 54.5% responded in writing to requests and 73% had an appeals process. We believe this should be standard practice across Scotland

⁵ Table 9 – Examples of carer's support under the 2013 Act

7.4 In consultation with carers and practitioners we heard of many good examples of family members being employed through a direct payment, resulting in better outcomes for the direct payment recipient. However, some concerns were expressed of potential negative consequences to family members being employed. These included the family placing less emphasis on developing the independence of the direct payment recipient, employment conditions being overlooked, disagreements leading to tension within families and concerns around the exploitation of vulnerable people. In order to address these concerns practitioners and carers recommended a good assessment process to determine if this is the best option for people, clear policies being put in place by local authorities and training and support for both parties in relation to their responsibilities.

8. Additional Points

8.1 While the statutory guidance includes a specific section on carers, there are few references to carers throughout the rest of the document. Since all the sections are relevant to carers it is important that this is reflected throughout.

8.2 There is no reference to carers as 'equal partners in care' it is important to establish this principle, as carers must be viewed as service providers and SDS as the delivery mechanism to provide carers with the resources they require to sustain them in their caring role.

8.3 Local authorities have a Power rather than a Duty to provide carers with SDS., following a carers assessment. We believe this may lead to a lack of equity across Scotland, with some local authorities not drawing on this power. We would like to see a review following implementation to assess whether the SDS Act has had a positive impact for carers and to identify best practice which can be shared, as well as any areas which have poor uptake

8.4 Where carers have reported concerns to us in relation to the implementation of SDS, this has generally been as a result of a poor assessment process and the agreed resource being of a lesser value to the resource currently provided by the local authority. This reduces choice and undermines the benefits of SDS and personalisation. We believe the guidance needs to be stronger in relation to how local authorities develop their Resource Allocation Systems. In particular it should be made clear that no assumptions should be made about the level of care unpaid carers are willing and able to provide and budgets for the direct payment recipient should not be reduced in the expectation that carers will be able to cover the deficit.

8.5 In implementing SDS for adults with a learning disability Glasgow has adopted a whole systems approach, making it a requirement for all service users to go through an assessment and resource allocation process before deciding on the resource available to them to address the outcomes in their care plan. Glasgow has argued that it is required to 'free up' resources in advance of the Act coming into force in April 2014 and have already planned the closure of three learning disability day services in order to facilitate this process. They have said that they plan to undertake a co-produced review of learning disability services, yet have decided on the closures in advance and before they have assessed the needs of the people who currently use the services. Both service users and carers have been campaigning against these closures and have called for a moratorium to allow their needs to be taken into account and their views to inform the process.

8.6 At the moment Glasgow appears to be an isolated example, but we have concerns that other local authorities will follow their lead and adopt a whole system approach to the implementation of SDS when the Act is introduced. Glasgow's approach is severely flawed as it is based on the assumption that the majority will choose a direct payment, despite evidence to the contrary. As a consequence, they have removed choice for many individuals who wish to continue with their existing service. The government needs to play a role in working with local authorities around the implementation of the Act. It must be made clear that this is not about the dismantling of existing services. SDS is still in its infancy and it will take time for the marketplace to respond to new demands. The transition must be handled sensitively and above all service users and carers must be at the heart of any service redesign.

8.7 We welcome longer term strategic solutions such as the market shaping strategy being developed by Edinburgh City Council which is exploring with people how communities can influence future social care provision to enable people to access a range of options. Edinburgh aims to gather intelligence of what provision people need and then influence the market to ensure providers meet these needs.

8.8 Another example is Joint Strategic Commissioning for Older People, which has begun to set standards for reshaping services and co-producing solutions with carers and service users. These same standards must be applied to the implementation of SDS

8.9 Finally, with carers being able to access SDS for the first time in their own right, combined with changes to the way services are delivered to the people they care for, it is essential that carers are able to access appropriate advice, support and training to help them navigate their way through the system. Many local carer organisations already provide this service, but will require ongoing resources to ensure they are able to respond to the increased demands which will result from the implementation of the Act. We recommend that additional funding is directed towards local carers centres for this purpose.

If you require any further information, supporting evidence or wish to consult with our members in relation to any of these issues, please don't hesitate to get in touch.

Yours sincerely



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The National Carer Organisations

Submission to the consultation on Regulations and Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013

Appendix 1 Summary of Consultation Responses

How we consulted with carers and other stakeholders

The National Carer Organisations Policy Group developed a briefing paper on the draft guidance and regulations, which was distributed widely to carers and other stakeholders. This outlined the key aspects of the guidance and regulations relating to carers and explained how people could contribute to the consultation

Stakeholders were given a choice of methods to contribute to the consultation. This included an online survey, consultation events and a Webinar session. The table below provides further details

| | Numbers Participating | Geographical Area | Participants |
|----------------------|------------------------------|--------------------------|--------------------------|
| Online Survey | 248 | National | Carers and Practitioners |
| Webinar | 18 | National | Practitioners |
| Consultation Group 1 | 28 | National | Carers and Practitioners |
| Consultation Group 2 | 10 | Glasgow | Carers |
| Consultation Group 3 | 6 | West Lothian | Carers |
| Consultation Group 4 | 12 | Edinburgh | Carers |
| Consultation Group 5 | 4 | East Dunbartonshire | Carers |
| Consultation Group 6 | 10 | Renfrewshire | Carers |

In total 336 people contributed to the consultation. Responses were received from carers, staff from carer organisations, other third sector organisations and lead officers from local authorities and the health service. There was a good geographical spread, including responses from remote and island communities.

Methodology

The consultation focused on several key issues for carers, mostly relating to charging and short break services. Eight questions were devised and these were used both in the online survey and through the use of message boards at consultation events. Respondents were also encouraged to provide further information and to illustrate their views by drawing on their personal experience, either as a carer or as a staff member supporting carers.

The Webinar session was less interactive and included additional information on other aspects of the guidance and regulations. Those who participated were encouraged to contribute their response to the consultation, either via the NCO survey, or through their own submission.

Summary of Responses

This report collates the responses and includes a sample of the comments we received. A full version of the online survey is also available. These responses have helped to inform our joint submission.

1. Carers should not be charged for the support they receive to help them in their caring role.

| | Group 1 | Group 2 | Group 3 | Group 4 | Group 5 | Group 6 | Survey | Total | % Breakdown |
|----------------------------|---------|---------|---------|---------|---------|---------|--------|-------|-------------|
| Strongly Agree | 27 | 9 | 6 | 12 | 4 | 10 | 206 | 274 | 87% |
| Agree | | | | | | | 30 | 30 | 9% |
| Disagree | | | | | | | 4 | 4 | 1% |
| Strongly Disagree | | | | | | | 4 | 4 | 1% |
| Neither Agree nor Disagree | | | | | | | 4 | 4 | 1% |

Additional Comments:

Unpaid carers are a major source of unpaid labour. They should be paid rather than charged

The law intimates that carers should be recognised as key partners

I agree with this statement. Many carers would not be able to pay towards costs as Carers Allowance is barely enough to live on

Carers don't choose their role – it just happens – so they should be given the help they need

The extra cost of caring is hard enough to cope with without being charged for 'Help to Care'

Carers save the NHS large sums of money. Carers are unpaid and if they did not carry out this unpaid work the NHS/Social Services would have to employ /train staff to take over their role.

I am a carer for my husband and we, as a couple cannot at the moment afford any help with care. I receive carers allowance but as this 'replaces' my earnings money is tight.

Caring for someone with additional needs provides its own stresses without the added stress of asking ones self if can afford additional support for carers themselves.

I have already had to give up work to fulfill my caring responsibilities, life is tough enough without facing poverty

This is fundamentally an issue of equality. Already carers make a range of sacrifices, including bearing financial costs, so to add to this would be very unjust, and add to existing inequalities.

Most carers are already on some form of benefit and struggling to make ends meet as it is without having to incur charges. It may be a case of having to refuse any form of help because they cannot afford it, which is not helpful to either the carer or the person being cared for.

Caring for someone with a disability at home has additional expenses, heating, washing soiled clothes or replacements for it

Carers are financially disadvantaged by the very fact that they are Carers! Any help/support should be given freely . This will enable family carers to continue caring. Remember the amount of money it would cost the country if carers were not around!!

Carers are left hugely out of pocket through having to pay for Day Services. A lot of costs are not taking into account, for example a parent with an adult child who gets weekly (10 hour for example) support will have to pay towards this, have money for the activities (and possibly cover the cost of the carer) and will also have to pay the additional cost for respite.

There is a need for very clear guidance on what a carer should and should not be charged for as what Government say and local authorities do can look very different.

2. When a carer is getting respite or a short break from caring, the cost of replacement care should not be passed on to the person they care for.

| | Group 1 | Group 2 | Group 3 | Group 4 | Group 5 | Group 6 | Survey | Total | % Breakdown |
|----------------------------|---------|---------|---------|---------|---------|---------|--------|-------|-------------|
| Strongly Agree | 28 | 9 | 6 | 12 | 4 | 4 | 177 | 240 | 76% |
| Agree | | | | | | 6 | 38 | 44 | 14% |
| Disagree | | | | | | | 13 | 13 | 4% |
| Strongly Disagree | | | | | | | 6 | 6 | 2% |
| Neither Agree nor Disagree | | | | | | | 13 | 13 | 4% |

Additional Comments:

Carers breaks are essential. This must be built in otherwise carers become unwell themselves.

In our case this would be my wife. Essentially this would be me paying for my break so it would be ridiculous, I wouldn't get a break.

Respite is for my health and sanity!

The carer should be treated as an individual in their own right and no burden passed on to the person they care for. Again this will be a barrier for carers as they will prioritise the needs of the cared for above their own and will not want to see their income/savings affected. Also the financial savings made by carers in the long run can surely offset the cost of providing replacement care.

This may deter carers from having a much needed break.

Not only would families be unlikely to meet the costs for the short breaks with the monies they receive but they may in turn be likely to refuse the break, leading to more families breaking down in their ability to continue to care.

In my experience the cared for person does not often wish to leave their home for respite and yet it is often the only way the carer can get a break. Why should they have to pay for the inconvenience of leaving home when it is not their choice?

My point at question one- and if the person being cared for refuses to pay for the carer to have a break "after all why do they need it" then the carer does not get a break.

If the cared for has some means of paying for the respite care or the carer has benefits or funding in place and it can be means tested I think a contribution should be made.

If the person in receipt of care were to be charged, most carers would not dare to have a break, or would be seriously concerned over the impact of their break on the person they care for. Such a measure would have a very negative effect and be likely to be counter-productive!

Most carers would feel guilty if the person they cared for had to pay for a replacement. I feel most of them just wouldn't go for respite if that were the case.

Respite my wife receives allows me to clean the house, do the garden. I also get out for a wee walk and speak to friends. But if I could afford it I would pay, respite helps so much.

3. It is reasonable to expect carers to ask friends and family to step in and provide support before they ask the local authority for help.

| | Group 1 | Group 2 | Group 3 | Group 4 | Group 5 | Group 6 | Survey | Total | % Breakdown |
|----------------------------|---------|---------|---------|---------|---------|---------|--------|-------|-------------|
| Strongly Agree | | | | | | | 21 | 21 | 7% |
| Agree | 2 | | | 1 | | 5 | 61 | 69 | 22% |
| Disagree | 3 | 7 | | | | 1 | 59 | 70 | 22% |
| Strongly Disagree | 19 | 3 | 6 | 10 | 4 | 4 | 76 | 122 | 39% |
| Neither Agree nor Disagree | | | | 1 | | | 31 | 32 | 10% |

Additional Comments, also incorporating Question 4:

Are there particular reasons you can think of that might prevent carers receiving short break support from family and friends, or circumstances where this would be inappropriate?

The two people who I care for would not like anyone else within the family to deal with there personal needs. The same goes for friends. It is a difficult thing to force on someone.

This trivialises caring – carers build up huge skills and family and friends cannot always replicate this even if they have the best of intentions

I was ill and needed an ambulance and my wife (cared for) had to come as well. The hospital looked after her whilst I had an emergency op but she was sent home in a taxi before I was discharged. No information was provided to other family members about the care/medication she needed so I had to keep managing the situation after my operation and before I got home. I was desperate to leave hospital even though I wasn't well.

Carers are already under pressure, it's not fair to also pressure family and friends

Sometimes in regard to mental ill health it may be more appropriate to seek support from family and friends

In some circumstances and if it is only a 'one off' it may be reasonable for other family members to 'step in' rather than someone no one knows from Local Authority

What do you do if relations are not near you. Some friends just say "put him in a nursing home"

If extended family are close then usually they are involved anyway

Strongly disagree – caring should be a choice not something people are "expected to do"

I feel I would rather get help from authority as my parents are in their 70's as are others. Also, other family members are full time workers

Your family and friends should be just that and not an extension of carers

Family may feel pressured to take on this role which could have a negative impact on relationships

Person with Mental Health issues may not trust others

This would assume that the role of carer can just be passed on to anyone– as if it's not a specialist role, that anyone could do it. As carers we are semi-professional and this statement devalues the job of a carer to an 'amateur'.

Increases risk of harm to children and vulnerable adults

Assumes a consistent unfluctuating level of care

My daughter's two older sisters do come home to help look after their sister but they both work full-time in very stressful jobs in Aberdeen and Birmingham and they need to have a holiday themselves: so it is not very fair to ask them to do it very often.

We are in a position where there are no family or friends who would step in to help.

For some people, asking for help is to them an admission of failure. This would be worse if there was an expectation that they ask friends and family first. Also there should be an expectation that the local authority could advise on range of support available and also make a dispassionate assessment of what is needed.

At the moment my family do step in. We are not however able to pay them even expenses (petrol etc.) and deduct this from earnings with regard to carers allowance as we would be able to do with local authority care. Another example of unpaid care on the cheap for government!

If an informal carer has support from friends or family who can assist in the care provided for a person, all's good and well. However it should not be determined that a person will be cared for simply because they have a social network or an extended family. Care is a very personal matter, and the opinions of the individual and the carer should determine the agenda of care provided and received at any given time

Not sure about your choice of words - if it is the same as "It is reasonable to assume that carers will ask friends and families to step in..... etc then I would agree. However the use of the word expect sounds more arbitrary and as families are not always able to provide support then that expectation may put them in a position where they feel that they cannot say no.

one of my daughter wants a life that is independent of her mum and dad, she wants to lead her own life why shouldn't she have this right? My other daughter has complex needs, family and friends don't have the required skill level

Agree it is reasonable, but not a requirement and should never be a requirement. Many carers do not want to ask family or friends for various reasons, and many service users do not want other family members or friends involved. In these cases then carer has to approach local authority and should never be made to feel ashamed of having to do so.

As I am disabled I would feel that my dignity would be compromised if other members of my family or even worse a family friend was to deliver the care I require. My wife delivers my care and knows what I require if she cannot do this I would feel much more comfortable if a trained carer took over these duties

Very much depends on the disability. The legal implications of administering life saving medication and moving and handling is beyond most family members remit.

With special needs children it's all about familiarity, routine, feeling safe and being understood, with my son for example he has no recognisable speech and has his own way of communicating combined with sign language. Relatives in particular more of ten than not have known the person being cared for all their life and understand that person's needs.

'Expect' is a very strong word. Individuals with a strong family network, might be fortunate enough to be able to rely on their immediate family members for support. However, depending on the needs of the individual being cared for, it might in fact be unreasonable to assume that family members are comfortable in administering care/medication/support at the level required. Many

families we support do not have a close network of family and friends nearby due to recent relocation, or indeed because they live in a rural community. I'm sure if families could get support from their own network this would be preferred - but it is not always practical.

In most cases there are not family members available as they have work and their own commitments. Many carers do not have friends who have enough knowledge or understanding of their young persons condition. In fact making such demands can jeopardize friendships. Most importantly this sort of help cannot be guaranteed.

cannot ask my 30yr.old son to look after his sister because it is very inappropriate e.g. toilet and washing needs, dressing etc. He also works full-time based in Nottingham but travels abroad a lot for work : so again when he comes home it is for a holiday even though he does look after his sister but in a limited way! All grandparents are dead except for my mother who is 83 and she herself gets support from me. All other relatives live in England.

Friends may not be prepared to provide care, not trained. Friends can then turn away from carers cause they will be afraid they will be asked again, increased isolation

Our 30 year old son has complex needs and requires help with personal care. It is inappropriate for his only sister who lives abroad to be expected to do this. We have very few relatives and all are too old/unwilling to cope with his needs. Friends evaporate as soon as they are asked to help in this way . That's why we have had 7 day s in 28 years!!!!!!

On occasion perhaps but if it becomes a regular occurrence people do not want to commit and the carer becomes stressed.

Only if those friends and family have previously indicated a willingness and capability to do so.

My son would not want his elderly grandparents dealing with his personal care

5. The draft Regulations on waiving charges for support to carers states that where carers were assessed as experiencing 'social isolation' any replacement care (to give the carers time out) would be provided or commissioned by the local authority with no charge made.

Do you agree or disagree that 'social isolation' is an appropriate way of deciding whether replacement care should be charged for?

| | Group 1 | Group 2 | Group 3 | Group 4 | Group 5 | Group 6 | Survey | Total | % Breakdown |
|--|---------|---------|---------|---------|---------|---------|--------|-------|-------------|
|--|---------|---------|---------|---------|---------|---------|--------|-------|-------------|

| | | | | | | | | | |
|----------------------------|----|--|---|---|---|---|----|----|-----|
| Strongly Agree | | | | 9 | 4 | 1 | 75 | 89 | 30% |
| Agree | | | | 3 | | 7 | 64 | 74 | 25% |
| Disagree | 11 | | | | | | 39 | 50 | 17% |
| Strongly Disagree | 10 | | 6 | 1 | | | 46 | 63 | 21% |
| Neither Agree nor Disagree | | | | | | | 21 | 21 | 7% |

Additional Comments:

Social isolation should not be the only criteria

When you have a child with a severe disability you find out your circle of friends diminishes

Social isolation is only one issue. A thorough holistic assessment of family situation should be undertaken

Social isolation is only one of a long list of issues for carers and one being much worse off due to the recession and welfare humiliation and chaos. If you have no money you are automatically disenfranchised

All carers are isolated in different ways

This would be unfair on a carer who had family and friends around them that were not suitable to step in to care e.g. if the needs of the person being looked after were high and complex. As carers we need peace of mind that replacement care is competent, professional and has back up if need be.

I work full time in a responsible profession as a consultant in the Health Service. I also spent 27 hours a week caring. The support I am now receiving is becoming less and less with washing not even being done. I have therefore to employ somebody to do the person I care for washing and very basic cleaning. I am at the end of my tether having to fight for the bare minimum the stress has probably contributed to my developing cancer. More joined up support is required. I would LOVE somebody to say, "we can help with that" instead of "we cannot do that". I do have social interaction through work and would not consider myself isolated but I am terribly stressed and require respite for my own sanity!

I experience social isolation and at this current time immediate family have been extremely aggressive towards my family as the feel we are not handling things properly . But the real reason is that they are completely unaware how much you have to do to care f or someone with a long term disabling condition.

I do agree but how could it be assessed and measured?

Respite is needed by all carers, whether socially isolated or not. It should be an entitlement.

I would think that all carers experience `social isolation` anyway : so even tho` I said I strongly disagree all the carers that I know of experience `social isolation` because under normal circumstances my 22 y r. old daughter would have probably followed her brother and sisters to university and/or left home by now and I would hopefully have had the time and money to go off and do my own thing with my husband and not stuck at home in my `caring role` !

Social isolation should not be the sole criteria. Caring is very stressful. Due to my wife's condition, MS; she can be left alone f or short times but cannot do any thing. Social Services does not consider that she needs care throughout the time I might be away. I cannot relax, concentrate when I am away knowing she is on her own and therefore do not generally "socialise". I have mental health issues and this does not help. Social Services do not, therefore consider that I am "socially isolated". I need a break. I also need to be assured, from a mental health point of view, that I can take advantage of any respite.

How could you possibly measure social isolation in the first place? I feel that this method of assessment will deny carers the support they require. Furthermore, the fact that they are socially isolated or not, should not deny them a break from caring. Even carers with a large family find it extremely difficult to ask family members to help. This is a very dangerous method of assessment in my opinion, unless the power of assessment was given to the local Carers Centre's who would be the only people in a position of judgement in this area.

What exactly does social isolation mean? Who decides whether or not someone is socially isolated? There is nothing more lonely than having lots of people around but find yourself in a position where you don't want to or can't ask for support!

As from tomorrow when my son leaves school we will both become socially isolated, my Son does not like anyone to come into our home and I can not leave him on his own.

Defining social isolation could be difficult. I have previously been told that because I work, I have time away and therefore no need for respite. Presumably if you work you could not be described as socially isolated. The true isolation experienced by carers, eg that you lose track of peers because you simply can't do the same things/go to the sample places, is far more subtle than that.

I agree with this, however a large number of the carers we support would possibly not put themselves first in this way . They would be more likely to identify their child as being socially isolated, and consequently would be looking for increased opportunities for them to engage with peers. Many carers we support still do not recognise themselves as carers - they are parents first. Consequently , there would be a risk of many of these individuals not being able to access support they need if they are not ticking the correct boxes in local authority paper work.

Social isolation is only part of the problem Exhaustion is sometimes the major issue. The other major factor is the elderly carer who just can't cope to the same extent as they used to.

Social isolation is too vague a term.

Agree that this could be one of the factors but not the determining factor.

6. The draft Regulations recognise the benefits of carers taking breaks with the person they care for - away from the demands of their caring routines. Where the local authority assesses this need, then the regulations propose that the carer's short break costs should be fully met by the local authority plus any additional costs for equipment, agency care support, specialist transport that might be required to make the break possible.

| | Group 1 | Group 2 | Group 3 | Group 4 | Group 5 | Group 6 | Survey | Total | % Breakdown |
|----------------------------|---------|---------|---------|---------|---------|---------|--------|-------|-------------|
| Strongly Agree | 21 | 8 | | 11 | 4 | 1 | 123 | 168 | 55% |
| Agree | | 2 | 6 | | | 5 | 79 | 92 | 30% |
| Disagree | | | | | | 1 | 15 | 16 | 5% |
| Strongly Disagree | | | | | | | 6 | 6 | 2% |
| Neither Agree nor Disagree | | | | | | 1 | 22 | 23 | 7% |

7. The draft Regulations also recognise that a carer can benefit from a holiday or short break away from the person they care for. Where this is agreed through a carer's assessment, the regulations propose that the costs of the break(s) will be wholly met by the local authority.

| | Group 1 | Group 2 | Group 3 | Group 4 | Group 5 | Group 6 | Survey | Total | % Breakdown |
|----------------------------|---------|---------|---------|---------|---------|---------|--------|-------|-------------|
| Strongly Agree | 24 | | | 10 | 4 | | 110 | 148 | 50% |
| Agree | | | 6 | | | 7 | 64 | 77 | 26% |
| Disagree | | | | 1 | | 1 | 28 | 30 | 10% |
| Strongly Disagree | | | | | | | 11 | 11 | 4% |
| Neither Agree nor Disagree | | | | | | | 32 | 32 | 11% |

Additional Comments for Questions 6 and 7 combined:

Breaks are essential for the wellbeing of the whole family

What is cheaper – A carers break – or time spent in hospital with a nervous breakdown or depression

With social work putting more onus on care in the community and the closure of day care and nursing homes. Carers should definitely be given a break

No one should be excluded from the essential service because of financial circumstances

Carers need a break from their caring situation, but need to be reassured that the person they are looking after will be in a safe environment with qualified people

This would be brilliant, however, the corresponding respite costs need to be met. I think it would be a huge boost to have money for a break/holiday for my mum from LA, it would be an acknowledgement of all the care she does .

Carers of working age may not be able to work because of their caring commitment, some even caring 24/7 so they exist on income support or the new benefit on the princely sum of approximately £61 a week Could any one afford a holiday or break of any kind on that?

a small price to pay to keep carers health and more able to care

I would be quite happy to pay for my own holiday if i got one outwith my caring role, The LA is skint.

local budgets are under scrutiny and think it should be on a case by case assessment.

Carers deserve a great deal more than they currently receive. I do not, however, agree that they deserve free holidays. The respite care needs should be met by the local authorities but the carer holiday costs should be borne by the carer. The NHS, for example, does not pay for patient holidays when they are assessed that they "can benefit from a holiday or short break". If that were the case, no-one would ever pay for their holidays.

Depends on where the carer would like to go. Cant imagine is justified to spend public money to go for a wide trip! There should be some guidelines.

It would be a good idea to offer some form of support to allow the Carer to have a little time away to regroup and refresh themselves. Perhaps by offering to fund the cost of basic accommodation, or to make a Government Grant available- made pay able directly to a specific place of accommodation? But I don't think it is unreasonable for cares to make provisions for payment of some of the cost for their break away from caring.

I can't work as there is not enough appropriate support for my daughter, I do not have extra cash to fund breaks, yet I am saving the council thousands each week as my daughter requires a 2 to 1 support package , 24 / 7

This is 'pie in the sky'. Where will local authorities get the money to finance this?

I don't think the local authority should have to pay for the carers break, I think they should meet the cost of covering the care needs whilst the regular carer has a break.

In an ideal world yes - but I understand financial constraints - so for me, I think respite costs need to be met for all before thinking about holidays for carers. There are also pots of money available through charities for holidays.

Helps to sustain the caring role and is cost effective

If I want a break I want to go where I want to go and for as long as I want – I do not want to be restricted by what the local authority say because they are paying.

For all the reasons I have previously said. I have 3 children, 2 have a rare genetic syndrome and it can have an adverse affect on family life, my health and wellbeing. I have had 2 short breaks over the past 11 years and I have felt refreshed and ready for the continuing challenges ahead.

Local Authority can only afford to cover these costs if they were given the money by Government to help. It would not work if our local authority had to pay for this care via an already decreasing budget.

I strongly agree, providing eligibility criteria are met - those criteria should be the same across the country

Personally, It is more important to me my mum and my sister that my mum has a genuine break from my sister and equally my sister has a genuine break from my mum where she has to interact (in a supportive way) with other adults.

I have been on breaks with my disabled husband and had to pay through the nose for hire of equipment and carers but it allowed us to have a 'normal' holiday What a difference it made!

there are many low income working families where members are under severe pressure to make ends meet who do not have access to public funding of breaks from their day to day responsibilities. Any LA funding should be agreed on the basis of an assessment of need.

Ideally I think it would be good if there could be a bursary or grant towards a break but I think it is unrealistic to think the local authority could cover all costs! A grant towards a break would be helpful as it is definitely more expensive to go on holiday with a person with a disability, especially if you need somewhere adapted.

we had a break away last year where the cost of the cottage was paid for by the local authority but not the cost of two carers (needed for hoisting by their request) so it was not much of a break really as I had to be the second carer.

In the Isle of Lewis, the cost of travelling to mainland prohibits many Carers and Cared For from taking breaks

Several reasons to justify this: 1. Enabling families with a person with support needs to lead normal lives 2. the preventative factor of such breaks, with huge potential to strengthen relationships 3. a cost-benefit analysis would show the huge savings to NHS/LAs from the unpaid caring relationship which in purely economic terms warrants this investment

Q8 Is there anything else you'd like to say in relation to the Scottish Government consultation?

Getting a assessment is the problem and when you do have one done nothing changes

Social Work should not be the ones who decide who gets what. There should be some allowance for other professionals involved- who may have a more accurate picture to identify that a carer needs support. The families shouldn't then have to jump through social work hoops to get that support as they currently do.

I am absolutely delighted by this announcement - at last someone realises carers should not be charged- well done to the Scottish Government this decision aligns itself well with the removal of prescription charges. It can also allow a carer to continue to retain their employment when they are on the financial borderline. This will reduce the stress on the carer in particular if they were to reach a point of burnout.

Glad to see the govt recognising the role of carers

I'm interested that respite was raised at the Tories conference as a suggested entitlement - that's the right way ahead.

If these charges are waived where would the money come from as Local Authorities are already stretched.

Genuine partnership working with carers is essential. Carers aren't stupid - they know that there are not unlimited funds available - sharing openly and honestly with them the restrictions that have to be worked within would enable them to see how they could best use the resources available to them.

Local authorities should be obliged to provide the support that is outlined in the person's assessment, instead of carer's having to fight for their rights.

All of this sounds good in theory but if the Scottish Government is not prepared to make the money available to cover these costs then the Consultation is a waste of time and money .

I think it is an excellent consultation but worry that there will not be enough funding to support carers need



The National Carer Organisations comprise the following organisations: Carers Scotland, The Carers Trust, The Coalition of Carers in Scotland, Crossroads Scotland, MECOPP, Shared Care Scotland and the Scottish Young Carers Services Alliance

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