



## **Submission by the National Carers Organisations Group to the consultation on Regulations and Statutory Guidance to accompany the Social Care (Self-directed Support) (Scotland) Act 2013**

There are over 660,000 unpaid carers in Scotland<sup>1</sup> who save the government £10.3 billion every year, equivalent to more than three quarters of the entire budget of NHS Scotland<sup>2</sup>. Of these, 115,000 care full time, without pay, for over 50 hours a week – roughly equivalent to Scotland's total paid care workforce<sup>3</sup>. 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.

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.

The implementation of the Social Care (Self-directed Support) (Scotland) Act 2013 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.

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.

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.

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<sup>1</sup> Scottish Household Survey 2007/2008

<sup>2</sup> Valuing Carers, Carers UK. 2011

<sup>3</sup> Census 2001

## **How we consulted with carers and developed our submission**

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

In addition, we 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.

This response aims to highlight the 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.

The responses in this document are dealt with in the following order:

1. Response to the Draft Statutory Guidance on care and support
2. Response to the draft Self-directed Support (Direct Payments) (Scotland) Regulations 2013
3. Response to the Draft Carers (Waiving of Charges for Support) (Scotland) Regulations 2014
4. Response to the Draft Directions (The Carer's Assessment (Scotland) Directions 2014)

## **1. Response to the Draft Statutory Guidance on care and support**

### **Section 2: The supported person's pathway**

We are very much in favour of the 'pathway' layout of the support accessing process in this draft guidance. Each stage is clearly set out and it makes sense to view the journey as a process with distinct stages in order to aid understanding. With regard to support offered to carers, it is clear in the guidance that the assessment process is intended to be a conversation between social care professionals and the carer who is seeking support, and not merely a tick-box exercise. However, although the supported person's pathway is applicable to people with care needs and to carers who are also being supported, there is not any information on how the carer can fit in with the supported person's pathway when they are looking after someone rather than accessing support in their own right.

There is particular relevance in specifying the carer's involvement in Steps 3, 4 and 7. As part of Step 3, the carer will be involved in determining eligibility and assessment for support (as the support the carer can provide will affect how much support the person receives). Step 4 follows on from this and will also involve the carer in a similar way. Step 7, the review of support, will also involve the carer as their circumstances may have changed and they may be able to provide a different amount of care, which will affect the review of the statutory support that is offered to the person with care needs. The involvement of unpaid carers in support planning is made clear later in the document (Section 4, paragraph 33, 35) and it would be sensible to include these references throughout.

The unpaid carer's role in providing information and guidance when support is being planned for the person they care for is referenced within table 2; there is an opportunity to link the roles and responsibilities more closely between Tables 1 and 2 to make sure the carer's role is

### **Section 3: Values and Principles**

We appreciate that the introductory section of the guidance makes it clear that the document applies to unpaid carers who are seeking support as well as people with support needs, and also that the term 'supported person' can be read as inclusive of unpaid carers in this context. However, the values and principles section of the draft guidance are an ideal point to reiterate that the Social Care (self-directed support) (Scotland) Act extends self-directed support to unpaid carers in their own right. Paragraphs 11, 12, 13 and 14 should explicitly reference unpaid carers to ensure parity of the principles when applied to carers.

Table 3 contains a number of further statutory and good practice principles that underpin parts of the Act. Similarly to the points outlined above, there should be explicit reference to carers within some of the principles in table 3, particularly the principles of collaboration, informed choice, innovation, and responsibility. This would fit well with Table 4, where the principles of assessment do explicitly include carers.

## **Section 4: Eligibility and Assessment**

We would like to see more information in this section on the benefits of early preventative support. This is particularly required for inclusion in paragraphs 19 and 20, the 'low risk' bullet point in paragraph 22, more explicitly in paragraph 23, and paragraph 26.

We welcome the point made in paragraph 24 that if an individual is assessed as requiring services, then budgetary constraint should not be a factor in determining whether to meet these needs. This goes some way towards alleviating the potential gap in service provision that is created by S3 (4) of the Act. We also welcome the recognition that investment in universal and preventative services can prevent or delay the need for more formal support – as described above, this point should be made more clear throughout the whole section.

Whilst a number of local authorities in Scotland have been offering self-assessment to carers, there can be serious issues in relying on self-assessment as a starting point that is a 'gateway' to a full assessment. We welcome the clarification that self-assessment must not replace a further assessment with input and support from professionals, but it must be considered that carers will frequently under-estimate their own needs when self-assessing and it is the conversation with the social care or health professional that can draw out the impact that caring is having on a person's life, enabling better support to be put in place. It is for this reason that self-assessment must not be used as a gateway to accessing a further assessment. Self-assessment by definition is not a conversation between a professional and a supported person – a self-assessment must be seen as a tool to prepare for a full assessment and support must be given to complete the process.

## **Section 5: Support Planning**

There is little mention of the role of the unpaid carer within this section. Mention of the role of carers is needed throughout but particularly within sections 5.2 (Risk) and 5.3 (Resources).

By the very nature of caring, an unpaid carer is clearly a resource available to an individual exploring self-directed support. However, section 5.3 must include a clear statement about carers' choice and ability to care (including the level of care they are willing and able to provide) and the impact of demands placed upon them. This should include ensuring that carers are fully consulted and that they are offered a carers' assessment.

We know that carers are already being placed into unsustainable positions with budgets reduced, simply because the local authority decides that if a carer is available, then the person needs less support through self-directed support and thus indicative budget. This is often with insufficient consultation or discussion with the carer and with little understanding of a carer's right to choose to have a life outside caring, including to remain in employment. For example, carers have been told that they cannot specify the times where they will be able to provide care, making remaining in employment difficult if not impossible for them.

Moreover, the care a carer provides may in fact not be linked to the outcomes the individual wishes to achieve for themselves, e.g. the carer might provide much of the care at home but the outcome that is most sought is the ability of the person to participate in the community outwith the home and away from their carer.

This discussion is also relevant in section 5.2 (Risk). Any discussion on risk should include risks to the sustainability of the caring role.

### **Information and Support**

From our discussions with carers who are currently receiving or working through the SDS process with the person they care for, there is currently a particular issue with the information that carers (particularly those who are acting as guardians) receive about SDS. For example, carers involved in the Glasgow SDS process repeatedly say that they do not have a full understanding of the process and have not received any information to help them understand it better.

### **User led support and information**

The guidance should refer to sources of information and support services available for carers. However, there must be recognition of the capacity of carers centres to be able to respond to requests and referrals as some have already reported an increase in enquiries regarding self-directed support and are facing difficulties in providing sufficient capacity.

### **Resource Allocation Systems**

There is a lack of information within the draft Guidance on resource allocation. As noted earlier, carers report:

- a lack of information on the processes of SDS including resource allocation,
- reduced budgets on review without clear reasons as to why,
- a lack of clarity in challenging budgetary decisions and
- arbitrary decisions to reduce allocations offered on the basis of the person having an unpaid carer.

Whilst we recognise that there is no single approach prescribed in law, we believe that this guidance offers the Scottish Government an opportunity to provide real clarity on the best approaches, key principles for the development and implementation of local systems (including co-production and the involvement of carers as equal partners) and improved information for individuals and carers.

Local authorities must be instructed that they should not include arbitrary and often blanket decreases in the supported person's budget solely because that person has an unpaid carer.

### **Section 9.2: Assistance with understanding and making decisions**

There is a lack of clarity in paragraph 110 about which powers a person should have under the Adults with Incapacity (Scotland) Act 2000. It is unclear whether they would require both financial and welfare powers or whether this would differ depending on the situation. For example, where a decision is made that a direct payment would be the best way of meeting the supported person's outcomes,

guardians and attorneys would require both welfare and financial powers. Financial powers may not be required for Options 2 and 3 but welfare powers would be required.

In light of difficulties carers who are also have powers under the AWI Act have reported in, for example, being allowed to attend meetings or receive advocacy support in meetings, and in line with guidance on advocacy for carers, we would suggest adding a paragraph to discuss the need to offer appropriate support and advocacy. Carers and family members who also have relevant powers may require advocacy, other support and effective information in making decisions on behalf of the supported person. This is not a reflection on any ability to carry out their role but rather to assist them in negotiating effectively on behalf of the person they care for.

### **Section 9.3 Carers**

In the first instance, we believe that it is important that reference to carers, in line with their role in providing care for the supported person, are included throughout the guidance. Including a separate section on carers is important but having this as one of the few references and in the near the end in the further guidance section does not make the correct links between what are often complicated family lives, where despite options provided under self-directed support, carers often remain as the main provider of care and support.

Secondly, this section must emphasise that carers are equal partners in the provision of care and like other partners, require resources to sustain their caring role and maintain their own health and wellbeing. In line with Caring Together, support should also focus on carers' right to "have an identity beyond caring which can be found in employment, volunteering and leisure opportunities<sup>4</sup>." This applies equally to young carers<sup>5</sup> and in this case should also emphasise the need for young carers to sustain their education and have the same opportunities as their peers.

We would suggest that the following paragraphs require further explanation or rewording to ensure clarity.

**Paragraph 115:** We believe that the suggestion that an assessment rests on a "problem solving" approach is incorrect. A good quality carer assessment rests on an **open and honest** conversation between the professional and carer with a strong focus on *personal outcomes*.

**Paragraph 118:** A clear message is needed for local authorities that, if they decide not to take up their power to offer SDS to a carer, then they should not "do nothing". In line with guidance, the authority should ensure that the carer had access to other supports e.g. universal carers service, condition specific groups etc.

We are concerned about that statement that "Carers do not tend to 'down tools'." Whilst we recognise what this is intended to mean, we believe that the following paragraph would be more suitable and would reflect the careful consideration of whether or not to provide funded services:

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<sup>4</sup> Caring Together: The Carers Strategy for Scotland 2010-15, Scottish Government (para 10.16)  
<http://www.scotland.gov.uk/Publications/2010/07/23153304/5>

<sup>5</sup> Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015,  
<http://www.scotland.gov.uk/Publications/2010/07/23153304/0>

118. In deciding whether to provide funded services or support, the statutory agency should consider carefully the impact of their decision. Without the contribution of the carer, statutory agencies would otherwise have to step in with higher levels of support which would be considerably more costly. Senior managers should encourage professionals to exercise their own judgment whilst considering the outcomes carers wish to achieve and a preventative approach to supporting carers.

**Paragraph 121 and table 9:** The examples given within this table are poor and misleading. In particular, the example to provide a direct payment to offer housework services whilst a carer is recovering from a hip operation is particularly poor. Any carer who is recovering from such an operation would require support for themselves and replacement care to ensure that their recovery is a full one. Moreover, if a carer is discharged from hospital they would be entitled to care at home services to aid their recovery, normally for a period of 4 weeks.

Furthermore, in line with our comments on the consultation on regulations to waive charges for carers, the guidance, including these examples, must clearly differentiate between those services which a carer may choose through self-directed support in order to sustain them in their caring role or to achieve other personal outcomes, such as a short break, driving lessons, or practical help with housework and gardening and those universal services which a carer can currently access without an assessment or a direct payment. In particular, the example detailed in the draft guidance for directing available support and providing an individual service fund to purchase peer support sessions is, in our view, outwith the scope of self-directed support and is a core funded universal service for all carers.

We suggest the following replacement examples.

<p>Direct payment</p>	<ul style="list-style-type: none"> <li>• A carer who lives in a remote rural area is feeling increasingly isolated and depressed. She has no friends or family living nearby and her nearest carers' centre is hundreds of miles away. The carer uses a direct payment to pay for the installation of broadband and a tablet computer. This means she can keep in touch with her family and friends through Skype, particularly her grandchildren who live in Australia. She has also made friends with other carers on an online forum and she now feels more connected.</li>   <li>• A young carer who carers for his mother expresses that he has not been able to have the same opportunities as his peers. Whilst all his friends are learning to drive, he cannot because his mum cannot afford the cost and, because of his caring role, he cannot have a part-time job to save up to buy some. He thinks that having a driving licence would mean that the family could have a Motability car meaning which would help with a lot of the tasks around his caring role such as shopping and taking his mum to places. He also thinks if he was able to drive this would open up more job opportunities. The young carer uses the direct payment to pay for several driving lessons and the cost of his driving test.</li> </ul>
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Directing the available support	<ul style="list-style-type: none"> <li>• A carer has never had a break from caring. He would like to have a break of an afternoon each week to have a rest where he doesn't need to worry about the safety of the person he cares for. The carer receives a short break voucher as a form of "virtual break" which they use to purchase this regular short break.</li> <li>• The professional arranges for an individual service fund to be set up to support a carer. This carer has always been very house-proud. However, her husband has had a stroke and she is now providing care almost continuously. She is falling behind with housework and laundry and this is making her feel increasingly tired and depressed. The carer uses the individual service fund to purchase domestic help from an agency– someone to do the cleaning and ironing and assist with other domestic tasks. The carer also uses the individual service fund to pay for a fortnightly care attendant so that she can meet her daughter for lunch and have a break from caring.</li> </ul>
Arranged services	<ul style="list-style-type: none"> <li>• After the death of his father, the carer is finding caring for his Mum, who has dementia, emotionally draining and he is becoming very depressed. He is on a waiting list for NHS counselling services but has been told it may take a long time and his local carers' centre does not offer this service. The professional arranges for the carer to attend a private counsellor to help him manage issues of bereavement and of caring.</li> <li>• A carer talks about missing out on making new friends as she never has time because of her caring role. She expresses an interest in attending an art class in a local authority community centre. The professional arranges for the carer to attend the class and arranges replacement care for the person she cares for once a week.</li> </ul>

## **2. Response to the Draft Regulations on Direct Payments**

### **Q1: Calculation, payment and termination of direct payments**

We agree that if means testing must be carried out, it is more suitable to do this before the direct payment is made so that the recipient does not end up having to pay anything back.

Although the charges for direct payment users will be waived if the service is provided under the circumstances outlined in the Carers (Waiving of Charges for Support) (Scotland) Regulations 2014, we remain concerned that carers who look after their partner may have their income taken into account if their partner is assessed and means tested for some services. Current guidance on charging advises local authorities to consider whether the carer (as a supported person) has difficulty in meeting the charge due to their financial circumstances and that a holistic approach should be taken, considering the full impact of all prospective combined charges on the well-being and independence of the carer and the person they care for. Many carers and their families experience hardship, and if people who receive a direct payment have to contribute to this, it may influence their decision on whether to choose a direct payment. People often access very small amounts of support as direct payments but these have a significant impact for them. Requiring a contribution may not generate significant income for local authorities and may cost more in the administration required to carry out the means testing.

### **Q2: Appropriate/inappropriate circumstances of the employment of close relatives**

The National Carers Organisations welcome the recognition that there will be circumstances where it is both preferable and appropriate for a family member to be employed by the direct payment user to provide care and support. We find the list of factors setting out the circumstances (Regulation 9 Part 3) helpful and are in broad agreement with them. We believe their inclusion will provide greater transparency in decision making and significantly reduce local variations in practice which have, to date, relied upon individual interpretations of 'exceptional' circumstances. However, we would expect to see the term 'appropriate circumstances' used in the text of the regulations, in order to indicate the cultural shift in moving from exceptional circumstances only to appropriate circumstances.

Similarly, the inclusion of a 'discretionary' element where the circumstances fall outside the scope of the factors listed in Part 3 Regulation 9 but where a reasonable argument can be made for the employment of a family member is also welcomed. We believe that this will guard against too rigid an interpretation of the circumstances in which it may be appropriate to employ a family member.

We believe that the shift from 'exceptional' to 'appropriate' will increase choice and flexibility in the delivery of care and support practitioners to move away from viewing such arrangements as 'an option of last resort'. We would suggest that a duty is placed on local authorities to inform direct payment recipients of the option of employing a family member within the parameters set out in the Regulations, that all requests for the employment of family members through direct payments should be

considered without prejudice, that a full explanation is given if the request is denied and that an appeals/review process should be available.

Information from a survey conducted by MECOPP into the employment of family members highlighted that several local authorities already have such measures in place. The data can only give an indicative response due to the relatively low response rate (13 out of 32 local authorities) but it provides a baseline to build upon:

- 7 local authorities have a pre-existing policy in place regarding the employment of family members;
- 5 local authorities have no policy in place;
- 6 local authorities inform individuals in writing if the request is refused;
- 4 local authorities do not provide a written response;
- 8 local authorities have an appeals process in place; and,
- 2 local authorities have no appeals process.

The transition from informal carer to paid employee is a significant one which requires due consideration of the benefits and potential challenges if it is to achieve positive outcomes for both individuals. In the survey conducted by MECOPP, greater flexibility and continuity and consistency in the delivery of care were highlighted as major benefits. Concerns focused on the changing nature of the familial relationship, management of conflict to include termination of employment, ensuring quality of care and the 'blurring of the lines' between the formal paid role and any continuing informal role.

To ensure that best practice is developed to enable the employment of family members, we would recommend that individuals considering such arrangements have access to advice, information and support throughout the decision making process and beyond in their respective roles as employer and employee. Both the person who is employed to provide support and the person who is employing them will need to be fully aware of the benefits and consequences of the arrangement, as well as full access to information about the responsibilities of both parties, legislative requirements around health and safety, and how to bring the arrangement to an end.

With regard to the issue of 'capability' of the carer to meet the assessed need of the direct payment recipient, we are unclear as to how this will be determined. Given that in the majority of caring situations, the family carer is the primary care giver and will undertake tasks on a daily basis that will be part of the assessed need, we feel more clarity is required.

Further clarity is required in Section 10 (1) (b) as we are aware of situations where power of attorney is shared (for example, between two siblings who provide care for a parent) and one of the individuals who shares power of attorney is employed via a direct payment. Adequate safeguards are in place as one sibling has continuing powers and the other, who is employed through a direct payment, has welfare powers (that are not yet being exercised) and therefore there is no conflict of interest. We would caution that individual situations that are working well and maintaining good outcomes for both the supported person and the carer may be damaged if Section 10 (1) (b) is brought into force in its current form, and suggest that is only when a family member has sole guardianship or powers of attorney that

they are excepted from being employed, and/or local authorities make clear what safeguarding procedures are in place to ensure that people who are employing a family member through a direct payment are not taken advantage of.

#### **Q4: Restriction of access to direct payments**

It is not clear why individuals who are homeless or who are fleeing domestic abuse are not to be offered direct payments to access support. Further information on why this is the case would be useful.

It is more understandable why those who require support in relation to addictions are not to be offered direct payments, but it may be more suitable to look at assessments on an individual basis rather than imposing a blanket rule. Direct payments will require records to be kept of how the money is used, and for support that will be paid for through the payment to be arranged before the payment is received – any inconsistencies would soon be noticed. Many people with drug or alcohol addictions will require small amounts of support in order to remain in recovery, and restricting their access to direct payments may have a detrimental effect. We note that there are no such restrictions on a carer receiving a direct payment when they look after someone with a drug or alcohol addiction, and as such we would welcome further clarity on the reasoning behind this restriction.

#### **Q5: Restriction of access to direct payments in long term residential care**

Allowing people to access direct payments whilst they are living in residential accommodation allows them to continue with support and activities that they may have been using before moving to residential care. The activities provided by the accommodation may not suit everyone, and it is important to give people a choice, as is the ethos of the Social Care (self-directed support) Act.

It is important to note that for many carers, their caring role does not stop when the person they care for is taken into residential care, and in many cases they may face a larger financial and time burden if they have to travel further to the residential accommodation in order to spend time with the person who is living there. Support provided to these carers (such as help with taxi fares) is important to ensure that they can continue to provide care and meet their assessed outcomes.

#### **Q7: Further comments**

We wish to reiterate the belief that a duty should be placed on local authorities to inform direct payment recipients of the option of employing a family member within the parameters set out in the Regulations, that all requests for the employment of family members through direct payments should be considered without prejudice, that a full explanation is given if the request is denied and that an appeals/review process should be available.

It is also important that 'appropriate circumstances' is the named definition of the situations where a family member is able to be employed using a direct payment. This indicates that such a situation is not out of the ordinary (as implied by exceptional) but is the best situation to meet the outcomes.

Further clarity around Section 10 of the Regulations will also be appreciated due to the adverse effect it will have on carers and family members who have welfare powers of attorney and are employed through a direct payment.

#### **Q8: Financial costs and benefits of the Regulations**

A consequence of the increase in choice around support options is the capacity of information, advice and support agencies to offer up to date and accurate information to carers, service users and others. Many carers' services and organisations are already operating at full capacity and may struggle to keep up with demand. It is vital that the Scottish Government, local authorities, the voluntary sector and any other organisation that provides information and advice around self-directed support is presenting clear and consistent information and is able to signpost effectively. Carers' organisations, the first port of call for many people with caring responsibilities who are searching for information regarding self-directed support, must be adequately resourced to provide this information, advice and support.

### **3. Response to the Draft Carers (Waiving of Charges for Support) (Scotland) Regulations 2014**

The consultation document which sets out the regulations themselves together with guidance for local authorities is welcomed. The National Carer Organisations consulted with carers and practitioners from across Scotland in person at a range of events, including a webinar, and through an online survey. The full results of this survey are included in the appendices of this response.

The National Carer Organisations have made comments primarily on the supporting guidance to ensure that the regulations are as clear as possible and not open to interpretation that would be detrimental to carers. Some comments made refer to more than one section of this supporting guidance. We have suggested rewording where we believe this would better aid interpretation.

Not surprisingly, carers were significantly in favour of not being charged for services and support provided to them. 96% of those responding to the survey said that they agreed or strongly agreed that they should not be charged and spoke about the financial and personal penalties of caring and of the significant costs to the state if they did not provide care.

*“Often a carer has to work less than full time to support the person for whom they care. This saves the taxpayer and government coffers millions of pounds a year. Without help many of these people would be bed blocking in our already overstretched NHS. It is wrong to charge carers as it may result in abandoning the caring role to support themselves with the inevitable increase in costs to support the people they care for in institutions.”*

*“Carers give up their time, energy, health and financial resources to care for ANOTHER person. This saves the government a fortune in comparison to these people who cannot be independent having to have round the clock care packages or needing admittance to residential facilities. Carers have already made a huge sacrifice, which is usually significantly financially detrimental to them, so they should not be expected to be further disadvantaged by having to pay for help. Furthermore I think it would lead to a huge reduction in carers, who could no longer afford to care for their loved one, which would be more costly in the long run to the government.”*

#### **Questions 1 and 4 – 6**

##### **Breaks**

We welcome the guidance on in the circumstances where charges must be waived and where they may not be. However, we do not believe that this is sufficiently clear and would suggest that Page 4, paragraph 9 be amended to read:

Lines 1 to 6 discuss waiving charges for breaks for carers in certain circumstances. In summary the following applies:

In relation to breaks, where a carer’s assessment determines that the following will produce the best outcomes, the local authority must waive charges for the following costs:

- The cost of a short break or break away for the carer or young carer away from the person they care for.
- The costs of transportation to short breaks or breaks for the carer or young carer.
- Any costs relating to the provision of a replacement care service which would facilitate a carer to have a short break from their caring responsibilities.
- The cost to the carer or young carer of a holiday or break together
- Any additional costs of such a holiday or break including, for example, specialist equipment or more accessible rooms

In the event that any care services are provided to **mainly meet** the assessed needs of the care recipient (to support social opportunities and to support independent living for example), but as a consequence deliver a break to the carer as a welcome by-product of the service, then existing charging policies would apply to the service user, but no charge direct or indirect will be applied to the carer.

Local authorities should build on and share best practice in implementing and delivering breaks in their area. Recent examples include the Time to Live Fund (delivered by Shared Care Scotland), Better Breaks (delivered by the Family Fund), short breaks vouchers and local short breaks bureaux. Strategies to support the delivery of such breaks in each area should be co-produced with carers.

We would note however, that without additional funding for the delivery of self-directed support for carers including breaks, we are concerned this may result in funding being severely rationed or diverted from elsewhere. The Scottish Government must monitor local authority delivery and be aware of and respond to any such unintended consequences in the delivery of breaks and other SDS support.

We also suggest that it would be helpful to reorder the breaks section to start with breaks and holidays together. Paragraphs 14 and 16 on pages 7 and 8 fit better together.

### **Breaks or Holidays Together (page 8)**

#### **Change to from p16 to p14**

Where a carer's assessment determines that a **break together** will produce the best outcomes, the local authority must meet the full cost of the holiday for the carer or young carer. Moreover, any additional costs resulting from the purchasing of additional care support, specialist equipment or special accommodation requirements that may be needed to facilitate this, will not be passed on to the carer or service user in the form of a charge.

### **Short Breaks (Respite) (page 7)**

#### **Change from p14 to p15**

When a carer's assessment determines that a short break or break away from the person they care for would be of benefit to the carer or young carer, the local authority will provide or arrange such support. In these circumstances,

the whole cost of the break will be met by the local authority. Examples of short breaks in these circumstances include holidays, attending weddings or family events, social activities, swimming or art lessons.

### **Change from p15 to p16**

Where it is agreed through the carers assessment that the carer will benefit from such short breaks, for example, weekly meetings with friends and that the local authority will provide support in that form, the cost of any transport involved (including taxi fares where appropriate) would be met by the local authority.

### **Replacement Care (page 9)**

The national carer organisations strongly believe that paragraphs 17 and 18 require to be rewritten. More than 61% of carers responding to our consultation said that they strongly disagreed or disagreed that there should be an expectation that they should organise friends, families or indeed volunteers to provide replacement care in order that they can have a break from caring. Whilst some carers already have some support from friends and family, they believed that this would place additional burdens on to these relationships and that often whilst individuals may be willing them simply do not have the skills to manage the complexity of needs that the cared-for person has. They noted that this would prevent them having a break at all. Many respondents also stated that they did not have family or friends close by.

*“Carers already struggle to find time and emotional energy to maintain bonds with family and friends. Putting pressure on others in order to get a break ourselves risks fracturing these relationships completely and adding further stress.”*

*“This is a very naive and misguided question. Usually the families and friends are already helping. For example I see my sister every week, and she often comes for tea to my house on a weekly basis. Respite weekends are the only times I get to speak with my mum on a one to one. I also work full time and cannot have my sister in the house for a full day as she cannot be left on her own for this amount of time.”*

*“Cared for person's needs are so complex that adequately trained person is needed. Family and friends may be willing but the burden would be too much. In order to have a real break from caring I would not be able to cope with the worry that a family member or friend would be unable to manage or the guilt should something go badly wrong.”*

There were some carers who were able to ask friends or family for support and would prefer this, but this should be a matter of choice and preference. Social isolation (and noted in paragraph 18) is irrelevant and unhelpful as a specified circumstance where the local authority should organise replacement care. The National Carer Organisations believe that the current wording of the guidance will create additional burdens and stress on carers, placing the too much of the onus onto carers, who by the local authority's own assessment, are in need of a break from the pressures of caring. Moreover, the current wording also suggests that all

replacement care is provided in the cared-for person's home which may not be the case as residential replacement care may be required.

Finally, we are unclear about the inclusion of volunteers as a source of “free” replacement care that a carer can organise. Whilst volunteers *may* be able to provide this support, it is likely that this will be part of a service that does have costs involved in the provision of volunteers, for example, through a third sector organisation that provides a service staffed by volunteers (e.g. befriending or care attendant schemes) who are provided with suitable training and appropriate vetting. Much more clarity is needed.

The guidance must be reworded to recognise responsibility should remain with the local authority to provide or commission replacement care (including that of volunteers) but that some carers may prefer (and have) friends or family willing and able to provide care.

### **Reword and combine paragraphs 17 and 18 to read:**

In order for carers or young carers to have a break away from their caring role without the cared-for person, then replacement care is often required. This replacement care enables the cared-for person to remain at home or, where necessary, in a homely environment without the carer or young carer. In some circumstances, a family member or friend may be able to provide this support. However, where this is not available, the Scottish Government expects local authorities to provide or commission replacement care. Any costs relating to this provision of a replacement care service which would facilitate a carer to have such a short break from their caring responsibilities must be waived by the local authority.

### **Breaks identified for the cared-for person within their care needs assessment**

For clarity, the National Carer Organisations believe it would also be helpful to specify the circumstances where charges may not be waived. The following paragraphs are suggested.

#### **Add 2 new paragraphs**

In the event where a break **for the cared for person** is identified within their own care needs assessment and thus care services are provided to **mainly meet** their assessed needs (to support social opportunities and to support independent living for example), but as a consequence deliver a break to the carer as a welcome by-product of the service, then existing charging policies would apply to the service user, but no charge direct or indirect will be applied to the carer.

However, there may be occasions when it would also be counter-productive to charge the service user if for example the application of a charge would prevent such a break. Local discretion will apply bearing in mind the implications of the impact to the carer to have a break as a result of this support and the additional services that might then be needed if the caring relationship breaks down.

## Question 2 (a)

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.

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.

This issue was raised with the Minister for Public Health, Michael Matheson 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.

Section 10 of the draft Guidance accompanying the Draft Carers Regulations 2014 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 gives a false impression of the types of support that would additionally provided through self-directed support. They should be removed due to the potential for them to be misinterpreted by local authorities.

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 carers' centre). This organisation purchases training or peer support sessions under the direction of the carer.*<sup>6</sup>

We believe the regulations and guidance need to clearly differentiate between those services which a carer may choose through self-directed support in order to sustain them in their caring role or to achieve other personal outcomes, such as a short break, driving lessons, or practical help with housework and gardening and **those services which a carer can currently access without an assessment or a direct payment.**

Notwithstanding the arguments above, where the waiving of a charge for information and advice is mentioned, there is a need to be clear that this does not include legal advice.

### **Question 2 and 3 (a)**

#### **Paragraph 10, bullet 7 and paragraphs 12/13 – Cost of taxi and driving lessons if special circumstances**

The National Carer Organisations are greatly concerned by the use of the terms “special circumstances” and “exceptional circumstances”. The use of these terms may place a barrier to carers for whom it is quite reasonable that they use a taxi. Location may be an issue but so too could timings of public transport. Regarding the example of an art class – it may be perfectly possible to get to and take part in the class if public transport that fits in when this is available but if it is not, then it becomes problematic. This does not just apply to remote locations or those with poor public transport or where public transport does not fit in with the opportunity and the caring role.

Moreover, the example given in paragraph 12 (bullet 2) of a taxi to take the cared-for person to hospital appointments is misleading. If an individual requires transport to hospital appointments and there is insufficient public transport or their needs require it, this is the responsibility of the NHS. Patient transport (including volunteer drivers) should be arranged or the hospital should arrange suitable transport, including funding taxis for *the patient*. In these circumstances carers should be advised of help available with arranging patient transport or with transport costs and how to apply for this support.

In addition, in relation to driving lessons, the use of the term special or exceptional circumstances does not fit in with an outcome focused approach. A carers' assessment should look at achieving best outcomes in both support for caring and support for the carer's own health and wellbeing. The opportunity to have driving lessons should be seen as part of support for a carer to have a life of their own and not solely about their caring role. In particular this may be something that would be beneficial to young carers as part of their ongoing development.

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<sup>6</sup> Table 9 – Examples of carer's support under the 2013 Act

We suggest rewording of this bullet and paragraphs 12 and 13 to read:

12. It might be decided following a Carers Assessment that the local authority will provide a carer with financial support to help pay for taxi fares. This might be, for example, in the following circumstances:

- Where the carer cannot rely on the public bus service to take him or her to, for example, an art class or other social or leisure opportunity
- Where a carer cannot drive a car and there is limited public transport.

13. It might similarly be decided following a carer's assessment that it would be helpful for the carer to be able to drive a car and that the local authority will provide support in the form of driving lessons up to an agreed financial limit. This may have multiple benefits in supporting the carer in their caring role e.g. ease of transport to appointments, shopping, reducing isolation and to support carers own wellbeing e.g. enhancing employment prospects for a young carer.

Whilst this support may not be the norm, local authorities should consider both driving lessons and taxis where it appears reasonable and practicable.

#### **Question 2(d)**

**Paragraph 11:** The examples provided in paragraph 11 are misleading. Providing gardening or housework support to a carer is not to provide more time to provide personal care to the cared-for person but rather to reduce some of the burden a carer experiences in addition to caring or that impacts on their ability to provide care. It may also assist in freeing up time for the carer to help improve their wellbeing and quality of life. We suggest that paragraph 11 reads:

11. Many carers have multiple responsibilities over and above their caring role and may need assistance with practical aspects of their lives to support their health and wellbeing. For example, it would be perfectly reasonable for a local authority to provide or commission help with housework and gardening to help reduce physical and emotional stress on the carer. When this support is provided to carers, it will be free of charge.

#### **Question 7**

##### **Additional information**

The National Carer Organisations believe that clarity is required in this section. The guidance would benefit from some rewording to reflect self-directed support itself and also the role of third sector. It would be helpful to reorder paragraphs 19 and 20 and add additional information within this section to aid this.

##### **Change paragraph 20 to paragraph 19**

19. Charges will not be made for support provided to carers either directly by local authorities or commissioned by the local authority through other statutory, independent and third sector bodies. However, as outlined below, if a carer wishes to supplement and pay for support above the agreed level they

will receive through self-directed support, this is a matter entirely for the individual carer.

### **Change paragraph 19 to paragraph 20**

20. The support which carers will not be charged for will be agreed following a carers assessment. Any further support not to be charged for will also be agreed through revisiting the carer's assessment. Carers should be provided with information on how they can ask for a review of their carers' assessment and of plans to schedule regular reviews in line with guidance on carers' assessments.

We believe it would be helpful to discuss supplementing agreed non-chargeable support in a separate paragraph giving examples:

Charges will not be made for support provided to carers either directly by local authorities or commissioned by the local authority through other statutory, independent and third sector bodies. However, as outlined below, if a carer wishes to supplement and pay for support above the agreed level they will receive through self-directed support, this is a matter entirely for the individual carer. Examples could include another break, therapies etc. If a carer chooses to buy an additional holiday or short break, any replacement care for the cared for person whilst the carer is away may be charged for. However, there may be occasions when it would also be counter-productive to charge the service user if for example the application of a charge would prevent such a break or a carer's ability to access a service that would improve their wellbeing.<sup>7</sup>

### **Reword paragraph 21**

For clarity, this paragraph should be divided to reflect that carers as disabled people requiring community care services and carers income being taken into account in financial assessments are two separate issues. Moreover, issues around charging and spouse/partner carers should reflect currently CoSLA discussions on charging.

21. There are circumstances where individuals who are carers are charged but **these circumstances are not related to their role as carers**. This relates to where a carer is also a service user and, as such, local authorities' financial assessment and charging policies apply. Therefore, this is outwith the scope of these regulations and guidance. However, **charges must be waived for any support they receive in their caring role**.

### **Add new paragraphs**

Moreover, some local authorities also take the income of partners, which can include carers, into account when reaching decisions on the charging of services and support **to the service user**. This is an ambiguous area of the law and COSLA is undertaking further work with its partners to establish

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<sup>7</sup> As outlined in our response to Question 2(a)

whether the policy in this area can be clarified.<sup>8</sup> This too is outwith the scope of these regulations and guidance.

Utilising CoSLA guidance on charging, local authorities should consider whether the carer (who in these circumstances is a supported person or partner) *has difficulty in meeting the charge for the service due to their financial circumstances. Local authorities should take a holistic approach, and consider the full impact of all prospective combined charges on the well-being and independence of the carer and the person they care for. Moreover, in designing charging policies, should give consideration to the impact of such policies on the well-being of carers, many of whom experience hardship.*<sup>9</sup>

#### 4. Draft Directions (The Carer's Assessment (Scotland) Directions 2014)

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 to greater consistency across Scotland and a more preventative approach to promoting and undertaking carers' assessments.

At the moment the number of carers' assessments being undertaken in Scotland varies greatly between local authority areas. 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.

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 they produce for carers are of primary importance and in order for the directions to achieve their aims, it is imperative that they are provided in context.

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*

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<sup>8</sup> COSLA, National Strategy and Guidance for Charges Applying to Non-residential Social Care Services 2012/13

<sup>9</sup> COSLA, National Strategy and Guidance for Charges Applying to Non-residential Social Care Services 2012/13

*provided directly to the carer.*<sup>10</sup>

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.

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 which should receive more prominence and be included within an introduction.

## **The National Carer Organisations**

**July 2013**

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<sup>10</sup> Community Care and Health (Scotland) Act 2002. New Statutory Rights for Carers Guidance