



Carers Trust consultation response

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

About Carers Trust in Scotland

Carers Trust works to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems. With our Network Partners, we aim to ensure that information, advice and practical support are available to all carers across Scotland. Together with our Network Partners, we provide access to desperately-needed breaks, information and advice and education, training and employment opportunities. We help carers to maintain their own health and wellbeing and support them so they do not feel isolated. Our Network Partners benefit from the provision of grants, our work to improve carers services and we help carers make their needs and voices heard and provide someone to talk to, in person and online.

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.

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 successful delivery of self-directed support across Scotland, translating the vision of personalisation into reality.

About the consultation response

The National Carer Organisations developed a briefing paper on the draft guidance and regulations which was distributed widely to carers and other stakeholders.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

[Carers Trust is a registered charity in England and Wales \(1145181\) and in Scotland \(SC042870\).](#)
[Carers Trust in Scotland is known as The Princess Royal Trust for Carers in Scotland.](#)
[Registered as a company limited by guarantee in England and Wales No. 7697170.](#)
[Registered office: 32–36 Loman Street, London SE1 0EH.](#)

Carers Trust

this 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.

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 also referenced within table 2; there is an opportunity to link the roles and responsibilities more closely between Tables 1 and 2.

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. Paragraphs 11, 12, 13

Carers Trust

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 options. However, section 5.3 must include a clear statement about carers' choice and ability to care (including the level of care

Carers Trust

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.

Furthermore, 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.

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
- 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 also have powers under the AWI Act have reported (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 opportunities¹." This applies equally to young carers² 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

¹ Caring Together: The Carers Strategy for Scotland 2010-15, Scottish Government (para 10.16)
<http://www.scotland.gov.uk/Publications/2010/07/23153304/5>

² Getting it Right for Young Carers: The Young Carers Strategy for Scotland 2010-2015,
<http://www.scotland.gov.uk/Publications/2010/07/23153304/0>

Carers Trust

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 has access to other supports e.g. universal carers services, condition-specific groups etc.

We are concerned about the 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:

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 of providing a direct payment to offer housework services whilst a carer is recovering from a hip operation is particularly poor. A 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.

Direct payment	<ul style="list-style-type: none">• A carer who lives in a remote rural area is feeling increasingly isolated and depressed. She has no friends or family living nearby
----------------	---

Carers Trust

	<p>and her nearest carers' centre is 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.</p> <ul style="list-style-type: none"> • 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.
Directing the available support	<ul style="list-style-type: none"> • 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. • 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.
Arranged services	<ul style="list-style-type: none"> • After the death of his father, a 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.

Carers Trust

	<ul style="list-style-type: none">• 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.
--	--

Response to the Draft Regulations on Direct Payments

Carers Trust

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.

Appropriate/inappropriate circumstances of the employment of close relatives

We 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. The list of factors setting out the circumstances are 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

Carers Trust

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, it is not clear 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

Carers Trust

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.

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, particularly when the draft Statutory Guidance states that *“Direct payments and individual service funds may deliver positive outcomes to individuals eligible for support due to homelessness, drug or alcohol addiction or because they are fleeing domestic abuse.”* Further information on why these individuals may not be suitable for this type of support 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.

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 or participating in 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.

Carers Trust

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.

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.

Carers Trust in Scotland July 2013

Contact: Heather Noller hnoller@carers.org / 0300 123 2008