The Social Care (Self-Directed Support) Bill

Carers Trust

1. Summary of key points & recommendations

1.1 Principles / Framework

There is an opportunity to amend the legislation to include a principle which recognises carers as equal partners in care. We believe this would build on existing recognition of carers in policy terms and the principles outlined in supporting guidance for the 2002 Community Care and Health (Scotland) Act where carers are recognised as key partners in providing care. This would send out a clear message that unpaid carers in Scotland and their contribution is both valued and supported.

1.2 Provisions Relating to Adult Carers

We would urge the Committee to consider and recommend a strengthening of the Bill to offer a duty - and not a discretionary power – to recognise and support carers. We would further recommend, in line with the 2011 recent Law Commission review of Adult Social Care (England) that every carer should have access to an assessment and the offer of support proportionate to their needs. Experienced carers’ organisations such as Carers’ Centres can contribute directly to this, ensuring carers are identified, assessed and supported in their caring role and to have a life outside of caring.

1.3 Provisions Relating to Information and Advice

Information and advice is critical; carers and their families need to have access to clear information and advice about the options for support and what the Bill itself will mean in practice. This needs to be impartial, and from a carers’ perspective must come from a specialist carers’ organisation such as a Carers’ Centre where staff will have built up relationships with families and understand the needs of carers. Carers’ Centres in Scotland are already preparing for this by putting in place training around Self-Directed Support (SDS) for unpaid carers and the centre’s staff teams.

The capacity of these organisations must be supported.

1.4 Effective Assessment and Involvement of Unpaid Carers/Families

The need to effectively assess families’ situations is vital and in doing so, we cannot lose sight of the needs of unpaid carers. This is vital to achieving successful outcomes for SDS. Carers and their families must be directly involved in the local implementation of the Bill and in local authorities’ work to expand personalisation.

1.5 Real Choice
The underlying intention of the SDS Bill is that people should have real choice in how social care/support is delivered. However, self-directed support will not suit everyone and carers may not want to take on the additional responsibility of for example employing Personal Assistants, accounting and managing the delivery of services. Families who choose to retain existing packages should not have to be reassessed or go through a Resource Allocation System.

The principle of choice underpinning the Bill must also extend to carers’ right to choose to care/not to care.

1.6 Self-Directed Support and Local Cuts

Moving towards more personalised services cannot sit alongside local cuts. What Self-Directed Support can offer is more effective use of resources as services more fully meet the needs of unpaid carers and their families.

1.7 Charging

The Self-Directed Support Bill opens up the possibility that unpaid carers could be charged for services which help support them in their caring role. **We strongly oppose this provision.** As key providers of health and social care, it is wrong that carers might be expected to contribute to the costs of services which enable them to maintain their caring role and their own health and wellbeing. **Plans to integrate health and social care services may provide a good opportunity to look at how charging operates in Scotland.**

1.8 Young Carers

The needs of young carers must not be lost in assessment processes for Self Directed Support. The potential impact of Self Directed Support for young carers needs to be considered – e.g. will they end up managing personal budgets for family members on top of any current caring responsibilities?

1.9 Employing Family Members to Provide Care through Direct Payments

In line with other carer organisation respondents, we would ask the Committee to recognise the need to strengthen existing regulations relating to employment of close relatives through Direct Payments.

1.10 Mental Health and SDS

We would urge the Committee to consider how carers and their families dealing with mental ill health can get access to SDS and to take note of points raised in section 8.5 of this submission.

2. Introduction

2.1 The Princess Royal Trust for Carers in Scotland (part of Carers Trust – see appendix 2) welcomes the opportunity to present a written submission to the Health and Sport Committee for Stage 1 of the Social Care (Self-Directed Support) Bill. The Princess Royal Trust for Carers in Scotland (PRTC)
currently helps some 53,000 carers and young carers cope by giving them information, support and advice through our work with the unique network of Carers’ Centres and young carers’ services. Additional support is provided through our interactive websites, www.carers.org and www.youngcarers.net and partnership work with smaller conditions specific organisations. We have been involved in the development of the Bill through the Bill Steering Group and have focussed our involvement on the needs of Scotland’s unpaid carers. Our submission is drawn from consultation with our Network Partners, carers and other key stakeholders.

2.2 It is important to point out that the current Government has strongly progressed support for carers both directly and through local authorities and health boards in a range of ways, not least of these being through increased investment in carer support e.g. through the Change Fund, Carer Information Strategy funding and through short breaks. The Bill presents the next stage on a journey to ensure carers across Scotland are effectively and consistently recognised and supported to have a life of their own and to maintain their own health and wellbeing.

2.3 Our starting point is that supporting unpaid carers makes good economic sense and that the Scottish Government has a significant opportunity to strengthen the rights of unpaid carers by delivering a duty to support carers through local authorities. Our contribution highlights some key issues which we would ask the Committee to consider both in seeking oral evidence and in pulling together its’ Stage 1 report.


3.1 We support the Bill’s intentions and principles:

- To offer more choice and control through a range of Self-Directed Support options;
- To ensure people have the information they need to make an informed choice; and
- To ensure there are mechanisms to review people’s situations as and when needed/when circumstances change.

The Bill presents a clear direction of travel, and seeks to empower people to have more choice and control. The challenge will be in moving from legislation to implementation both for service users and unpaid carers, especially in the current financial climate.

3.2 Aligned to the Bill and the Self-Directed Support Strategy, we very much welcome the additional investment from the Scottish Government to help kick-start change at local level. The PRTC and Carers’ Centres in Scotland, will work hard alongside statutory and other voluntary sector partners to help carers (and their families) understand and make informed choices about Self-Directed Support.
3.3 For service users, bringing the Bill’s principles to life is driven by legal duties. This is different for unpaid carers (Section 4). Supporting guidance for the 2002 Community Care and Health Act acknowledges the principle of carers being treated as key partners in care.\(^1\) Policy has moved on significantly since then and now recognises carers as equal partners in care.\(^2\) The next step would be to recognise carers as equal partners in care in legislation, sending out a clear message about the value of unpaid carers in Scotland and the need to support their contribution, as appropriate. We would urge the Committee to recommend an amendment to the legislation to include a principle which reflects this.

3.4 Access to social care remains confusing and difficult for many for a range of different reasons. The changes which the Bill seeks to drive will add new facets to social care and the Bill recognises that service users, carers and their family members need to have access to clear, impartial information and advice about support options and what the Bill itself means in practice.

3.5 For unpaid carers, that information should come from specialist carers’ organisations such as Carers’ Centres, through Carer Support Workers who will have built up a strong relationship with the family and who understand the specific role and needs of carers. Carers’ Centres in Scotland are already preparing the way by employing specialist staff (Dundee, Midlothian) and offering SDS training to unpaid carers (south Glasgow).

3.6 Driving change in the delivery of health and social care through Self-Directed Support must not be used as a mechanism to cut social care budgets and people’s packages at a local level. Effective assessment and involvement of individual service users and their carers – of families – is critical in this context and for the successful implementation of the legislation. Research in England around Self-Directed Support for people with mental health issues highlighted this (e.g. inappropriateness of assessment documentation for some individuals; waiting time from assessment to service input)\(^3\).

3.7 The recent experience of carers and their families in Glasgow clearly demonstrates the importance of effective assessment, illustrated by Carolan Connolly’s story (appendix 1). The rights of carers can and do sometimes get lost in assessment processes for Self-Directed Support\(^4\), particularly in self-assessment processes. The effective involvement of both service users and

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\(^1\) Carers and their Rights – Carers Scotland, 2006 – p11. Also CCD 2/2003 3.1.1
\(^2\) Caring Together – Carers Strategy for Scotland (July 2010)
\(^3\) Self Directed Support for Mental Health Service Users in West Sussex; West Sussex County Council and West Sussex NHS Primary Care Trust - 2009
\(^4\) The Individual Budget Pilot Projects: Impacts and Outcomes for Carers (The Princess Royal Trust for Carers/Crossroads Caring for Carers (April 2009)}
Provisions relating to adult carers: Making the Case for A Duty to Support Carers

4.1 The policy document accompanying the SDS Bill highlights the benefits to the public sector of good quality, well targeted support and the role it can have in reducing pressure on demand for services in health and social care. There is also a clear recognition that the right support, at the right time, can prevent crisis or emergency situations from developing. This prevention argument is critical to the SDS Bill, and underpins our argument to strengthen the Bill’s provisions for unpaid carers.

4.2 Unpaid carers are a key provider within the health and social care system and deliver substantial amounts of care. Not only is it cost effective to support carers in that role, it makes sense that they themselves have clear rights to support which in turn prevent them from suffering ill health and from being unable to continue caring. Having access to a life of their own can be tied up around the supports and services offered to family members – and so widening access to and improving services for service users through Self-Directed Support can directly benefit unpaid carers.

4.3 The Scottish Government and CoSLA have clearly acknowledged the preventative, economic and social benefits of supporting unpaid carers in their role. This is reflected in the Carers’ Strategy and the Self-Directed Support Strategy which acknowledge that support for carers can reduce demand on social care (and other) services – both from the perspective of the carer or the cared for person. The Carers’ Strategy also acknowledges that much more needs to be done to achieve practical support on a consistent and uniform basis, whilst outlining the need to support carers in the context of demographic change (pgs. 19-20).

4.4 At a recent meeting of the Cross Party Group on Carers (22 March 2012) the Scottish Government representative from the SDS Bill team outlined that part of the rationale for not creating a duty to support carers was down to cost. However, providing direct support to carers delivers clear economic and social benefits to statutory services. This is highlighted by a recent Social Return on Investment analysis of the work of Carers’ Centres and a related press release outlines the key benefits:

This gain in value arises from carers maintaining better physical and mental health by reducing stress and depression. In addition to this the person who is cared for is able to continue living at home while some carers may be able to continue working. The services targeting young carers play a crucial role in assisting [them] to continue education, find employment or receive training.

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5 As above
6 Self Directed Support Bill, Policy Memorandum
7 Caring Together (2010) – p21
[Carers' Centre Services] result in a real return to society, helping carers to continue to care confidently and safely. Carers provide support that is valued at £119bn a year. And services that help carers to continue caring are vital to society’s ability to look after its increasing elderly and disabled population.  

4.5 The cost effectiveness of carer support is recognised in the Welsh Assembly’s ongoing consultation on the Social Service (Wales) Bill. The consultation document clearly acknowledges the financial benefits of more consistent access to support and assessment of carers’ needs: 

4.6 We understand the Scottish Government’s rationale that a discretionary power to support carers can help drive front line change and empower professionals working with carers and their families. However, the Bill in its current format does not give parity of esteem between the rights of carers and the rights of service users - and indeed by giving local authorities a discretionary power, there is a risk that the current postcode lottery of support for carers will continue.

4.7 Lastly, there is a human rights perspective to consider. Carers should have access to the same rights to a life which helps them achieve their own potential, to achieve their own goals, to find or keep employment, and to maintain their own health and wellbeing. By not setting a standard through legislation to support carers more consistently, we are missing the opportunity to demonstrate the value of carers’ contribution and the need, as the Carers’ Strategy outlines, to support that more consistently across the country.

In light of this, we would urge the Committee to both consider and recommend a strengthening of the Bill to include a duty – and not a discretionary power – to recognise and support carers based on a Carers’ Assessment.

4.8 We would further recommend, in line with the 2011 recent Law Commission review of Adult Social Care (England) that access to a Carers’ Assessment should be widened beyond carers who provide or who are willing to provide “regular and substantial care”. Any carer should have access to an assessment and the offer of support proportionate to their needs. In line with current and developing practice, experienced carers’ organisations can help support this vision; indeed, Carers Centres already work in partnership with statutory bodies on this - such as in the Borders.

4.9 Recognising the current financial climate, the widening out of Carers’ Assessments to all carers could be phased in – through a power which can be enacted later or potentially through Statutory Guidance. It would be a positive step if the Government indicated a willingness to consider this, particularly in

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9 http://www.carers.org/news/value-carers-services-put-%C2%A3814m-year

light of the focus on preventative spend and the need to identify and support carers before they or their families reach breaking point.

4.10 We are aware of the concerns raised by other consultees that the number of Carers’ Assessments requested (and therefore requests for access to support) would increase because of the Bill. However, the Financial Memorandum does not agree with this and we agree with the analysis within this document. The work of Carers’ Centres through, for example, Carer Information Strategy funding has had a strong focus on identifying and in turn, assessing their needs through links with the Primary and Acute sectors.

4.11 We do however need to take into account the following points:

- Carers are sometimes still not informed of their right to an assessment and the assessment may not always affect positive change. (See Carolan Connolly’s story in appendix 1.)

- It is also important to consider who carries out the assessment and how this is then taken forward. Voluntary sector carers’ organisations carry out what is, effectively, a full Carers’ Assessment when supporting unpaid carers. Greater flexibility in carrying out assessments will hopefully increase the uptake and also assist with local planning of services based on a better understanding of local needs. Early involvement of Carers’ Centres can mean a more speedy response to immediate needs, and prevent the development of more expensive crisis situations. The role of specialist carers’ organisations such as Carers’ Centres must therefore be recognised and supported.

- Eligibility for a statutory (local authority) Carers’ Assessment is based on carers providing regular and substantial care which raises the question as to how this is interpreted? In the worst possible scenario, there is a risk that local authorities only offer a Carers’ Assessment to carers in crisis situations rather than in a way in which helps identify and prevent any issues developing earlier on.

- The range of local services available will be key in ensuring that choice and capacity of provision is available to those looking to take up SDS and the local authority role in developing this ‘market’ should not be underestimated.

- Local authorities should also have in place systems to clearly articulate how resources and budgets are prioritised and allocated to individuals, and what redress individuals might have if they choose to challenge the decision.

4.12 The Bill presents an opportunity to strengthen the importance of a Carers’ Assessment. There are positive opportunities to address the challenges outlined above through statutory guidance linked to the Bill and
through the development of practice guidance to strengthen the assessment process.

4.13 In addition, we concur with points made by other National Carer Organisations in their submissions to the Committee where they have outlined the importance of carers’ needs being recognised and supported through the assessment processes linked to SDS. The principle of choice underpinning the Bill must also extend to carers’ right to choose to care/not to care. Assumptions cannot be made about the carer’s willingness and ability to care.

4.14 Lastly, access to carer support must not be included in the service users’ Direct Payment or personal budget. It is important that the needs of the carer are supported separately – ensuring there is a strong duty to support carers would be a positive enabler in this context.

5. Charging

5.1 We strongly oppose the notion that carers, acknowledged as equal partners, could be charged for services which support them in their caring role. The Self-Directed Support Bill opens this up as a possibility. As an essential element of providing health, social care and other services in Scotland, it is wrong that unpaid carers may have to contribute to the costs of services which in turn can help them maintain their caring role and their own health and wellbeing – thereby reducing statutory interventions and costs.

5.2 Given that carers accessing Direct Payments / personal budgets may potentially only need relatively small amounts of money, to charge carers in this context is wrong and is likely to reduce any benefit gained from the Direct Payments / SDS investment to support the caring role.

5.3 On charging more widely, we would agree with the views of service user organisations, such as Independent Living in Scotland, that charging in Scotland needs to be fair and equitable, and that charging may well work against the vision and outcomes for Self-Directed Support. At a recent Carers’ Question Time event in Dundee (16 April), carers talked about the impact of charging for services provided to those they look after. Increased charging can push families into poverty; it can place an additional burden on unpaid carers who may have to provide more care when families can no longer afford to pay for social care services. Plans to integrate health and social care services may provide a good opportunity to look at how charging operates in Scotland.

6. Young Carers and Self Directed Support

6.1 Young carers over 16 will benefit from the provisions within the Bill and this is to be welcomed. As they are entitled to the same rights to an assessment as adults, some of the concerns we have raised above and indeed wider recognition of young carers and their specific needs is important.
6.2 Assessment of family situations and needs may show that a family is coping because of the support being provided by a young carer. The needs of the young carer can therefore become lost amongst this. Assessments for SDS and more widely must take account of the specific needs of a young carer and ensure they are supported to have a life of their own. For young carers under 16, this is particularly important.

6.3 The needs of the young person in this context should be considered paramount. Direct Payments / SDS may well benefit the service user but do they place additional burdens on a young carer who may, for example, already be managing the household budget?

7. Access to the Options – Other Support Mechanisms

7.1 Whilst we welcome the opportunity for carers to have access to Direct Payments or any of the other SDS options in their own right, it is important to note that there is another option which needs to be recognised – the range of direct support services already offered by voluntary sector carers’ organisations and Carers’ Centres to unpaid carers.

7.2 Such support must be recognised as a valid choice for unpaid carers and young carers. This type of support can sit alongside or indeed be offered in place of the options outlined above. The evidence base supporting the real impact and value (social and economic) of direct support for unpaid carers is strong.11

7.3 We have also heard, albeit anecdotally, that one local authority has mooted the idea of withdrawing its’ funding for the voluntary sector carer support infrastructure and instead provide carers with Direct Payments to purchase support. The danger in doing so is that an important element of preventative and on-going support for both carers and their families is removed. It would not be a huge step to assume that this could apply to user-led organisations which play a critical role in enabling and empowering disabled people.

8. Wider Issues & Challenges

8.1 The Impact of Personalisation / Self Directed Support

The principles underpinning the Bill are to be welcomed. Carers and people with disabilities themselves welcome the move towards services which work more effectively around their needs. However translation into reality can present significant challenges when, for example, the assessment of needs and resource allocation systems lead to cuts in personalised budgets which leave a gap in care as highlighted by the KM case in Cambridgeshire.12

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11 For example - Caring Together: The Carers' Strategy for Scotland e.g. page 23; Supporting Carers – The Case for Change (The Princess Royal Trust for Carers, 2011); Social Impact Evaluation of Five Carers’ Centres using Social Return on Investment (The Princess Royal Trust for Carers 2011).

12 http://www.guardian.co.uk/society/2012/feb/07/blind-man-care-funding-case
8.2 Much has been said about the experience of personalisation in Glasgow City, and the Committee will no doubt examine the experience of both carers and services users as part of their considerations.

8.3 Barriers to creating more personalised services

A SCIE report\textsuperscript{13} published earlier this year highlighted specific challenges which may arise in implementing the SDS Bill. These include:

- The need to develop a market of services which people can access in order to have real choice—this particularly affects rural areas. We need to consider how local markets can be stimulated.
- Funding cuts / impact of contractual changes— for services which deliver personalised services and support services. However, the impact of initiatives such as Carer Information Strategy funding has been positive in Scotland and has been utilised in Glasgow to help prepare carers and their families for personalisation.
- Inflexibility around the use of personal budgets / Direct Payments for families and for individuals. Work carried out by Voluntary Services Aberdeen and The Princess Royal Trust for Carers in 2009 highlighted the need for more flexibility in how Direct Payments can be used by families and the positive outcomes which emerge as a result—particularly for families in rural areas.\textsuperscript{14}

8.4 Employing Close Relatives to Care

Submissions from the Coalition of Carers in Scotland and other carer organisations will highlight the need to strengthen existing guidelines which cover the employment of close relatives to provide care and support through Direct Payments. The PRTC in Scotland supports this. Currently, carers and their families can find it difficult to take this option forward, even for a trial period. One carer who will submit written evidence to the Committee, Karen Hogg (East Lothian), outlines the processes and difficulties she faced when trying to set up Direct Payments which enabled her mother to employ her. Her story is powerful and the outcomes in her situation are very positive.

The existing regulations covering this provision will, we understand, be revised and we would urge the Committee to support stronger regulation which ensures that where a family chooses to use a Direct Payment in this way, they are supported and able to do so.

For some mental health service users, unpaid carers can be best placed to take on the role of personal assistant, therefore being employed may be a natural move. However this is not universal and may cause conflict of interest in some situations, such as procedures involving detaining a patient.

\textsuperscript{13} Social Care Institute for Excellence – Report 55 “People not processes: the future of personalisation and independent living. (Feb 2012)
\textsuperscript{14} A Study into the use of personalised services, notably Direct Payments, to benefit carers living in rurally isolated areas. (The Princess Royal Trust for Carers, Oct 2009)
8.5 Mental Health and Self-Directed Support

There is a need to ensure that staff in relevant agencies (statutory and non-statutory) are fully versed in the AWIA and Mental Health (Care and Treatment) Act and the Self-Directed Support Bill to ensure proper compliance and safeguards are in place.

Currently patients with mental disorders who are subject to compulsory measures under the Mental Health (Care & Treatment) Act, including those on community based compulsory treatment orders, are ineligible for Direct Payments. This is seen mainly to be due to the use of capacity testing in assessing whether a person can manage a Direct Payment. However, individuals may well have capacity to make choices about social care and support which is wider than medical treatment for mental health disorders. There is a need to consider how patients in these situations – and their carers – could potentially access SDS to help in rehabilitation, the development of independent living skills and to carers themselves to access vital support.

Unpaid carers can be left to cope with patients on a Community Compulsory Treatment Order, with limited service provision in place which may be difficult for the patient to engage with. Very often people recovering from mental illness need people they are familiar with and trust to help them. Supporting a patient about to become subject to community compulsory measures could enable them to put SDS in place, or resume it, prior to moving out of hospital. This might be of benefit to both service users, carers and their families.

One of the main components of SDS is the ability for service users to become more socially included in their community. This can be difficult for mental health service users where society still has opinions shaped by stigma and lack of understanding.

It is important to take account of the fluctuating nature of mental disorder. This can often mean periods where the caring role is more or less intense. What needs to be addressed is how quickly would a carer assessment pick this up and activate a Direct Payment to the carer, if one was deemed necessary, in this situation?

9. Conclusions

The Princess Royal Trust for Carers in Scotland (part of Carers Trust) continues to support the principles and intention behind the SDS Bill and will work with the Government to develop statutory regulations and guidance to support the implementation of the Bill, should it become law. Our longstanding aim is to work with the Government and other partners to ensure that the opportunities presented by the Bill are fully realised for carers.

We are happy to provide further information as needed and to assist the Committee as it considers the Bill.
Appendix – The Princess Royal Trust for Carers in Scotland

In April 2012, The Princess Royal Trust for Carers merged with Crossroads Care (England and Wales) to become Carers Trust. In Scotland, at the request of its Network Partners, the charity retains The Princess Royal Trust for Carers in Scotland brand and name.

The PRTC in Scotland currently helps some 53,000 carers and young carers cope by giving them information, support and advice through our work with the unique network of Carers’ Centres, young carers’ services and interactive websites, www.carers.org and www.youngcarers.net.

The Princess Royal Trust Carers in Scotland’s Network Partners throughout Scotland deliver services in almost all local authority areas from Orkney to the Borders. Each centre provides specific expertise for their particular area. The centres belong to the local carers and the services include:

- finding hidden carers through outreach in GP surgeries, hospital wards and schools
- finding the right information to provide personalised services
- campaigning for carers’ rights and entitlements and giving them a voice
- supporting carers emotionally
- helping to make caring a positive experience, by ensuring access to breaks, education or employment and the opportunity to share experiences with other carers.

Many Carers’ Centres also support young carers – children and young people under the age of 18 who take on caring roles and responsibilities that are inappropriate for someone of their age.

Support for young carers includes:
- help to find other sources of support so that fewer families rely on a child for vitally required care
- running clubs, activities and holidays that give young carers a break and time to be children
- giving one-to-one support and mentoring, together with raising awareness in schools
- educating and training teachers, doctors, youth worker and social workers to recognise the signs of a hidden caring role, offer a carer-friendly response and access to specialist help.

Carers Trust
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