Supporting Unpaid Carers as Preventative Spend

1. Introduction

1.1 The Princess Royal Trust for Carers and Carers Scotland is pleased to have the opportunity to submit comments and information relating to the preventative benefits and cost savings generated by supporting unpaid carers and young carers and on the Scottish Spending Review/Draft Budget published in September 2011.

1.2 The Princess Royal Trust for Carers works through a network of independent Carers’ Centres across the UK – 29 in Scotland, and over 140 UK wide. Many of these also run specialist young carers’ services. Carers Scotland works nationally through its helpline, information service and website and locally through a dedicated advocacy service in South West Glasgow. Both organisations work together closely on policy issues which impact on unpaid carers and young carers and in lobbying and campaigning in Scotland.

Together we reach tens of thousands of unpaid carers offering them practical support and advice which is preventative in nature. We also work with professionals from health, social care and other sectors to ensure they are aware of unpaid carers and why supporting them is cost effective and leads to positive outcomes for carers as individuals, for those who are cared for and for statutory services.

1.3 The aim of this submission is to outline why it is important to support unpaid carers, and the resulting economic and social benefits. Carer support has a clear preventative focus. We also provide some issues to consider in relation to unpaid carers in Scotland and the Draft Budget/Scottish Spending Review.

2. At the Heart of Carer Support in Scotland – What We Do

2.1 The Princess Royal Trust for Carers’ Network of Centres offers comprehensive, independent services in one place both for carers, communities and other organisations. There are core services delivered by Carers’ Centres across Scotland which clearly focus on improving the lives, health and wellbeing of unpaid carers and young carers with a wider impact on the lives of their families. Details of these services are included in Appendix 1.

2.2 Both Carers Scotland and The Princess Royal Trust for Carers have a key role to play nationally and locally in terms of the roll out of the Self Directed Support Strategy and in the development and implementation
of the planned Self Directed Support Bill. Both organisations are already preparing the way by running training for both carers and professionals to help them better understand the implications and benefits of self-directed support. Local carer organisations such as Carers’ Centres have a critical role to play in enabling carers to understand the total support infrastructure and in making informed choices about how support is delivered to them and to their families. Local advocacy support such as that provided by Carers Scotland and Carers Centres can prevent costly disputes by bringing professionals and families together to develop the services which best meet the needs of carers and those help to support.

2.3 There are other organisations which provide support to carers including condition-specific charities and community-based organisations. However, the unique service offering of Carers’ Centres has been recognised in, for example, Stirling, where a three year contract was awarded to Stirling Carers’ Centre during a planned full tendering process. In Bromley, a Conservative-controlled council in London, the local Carers’ Centre was awarded a seven-year contract. The reasons for doing so were as follows:

- There was no specialist expertise on carers within the council and it would cost more to develop that ‘in-house’
- Council policy is to commission externally as much as possible
- Carers are a group of people who will still be needing support long term into the future and will remain a feature of government policy
- There were no other potential providers and the Carers’ Centre has successfully worked in partnership with the council in the past
- The added value that a Carers’ Centre can bring through charitable fundraising and volunteering.

3. Why Support Unpaid Carers – Some Background and Key Facts

3.1 There are 657,000 unpaid adult carers in Scotland\(^1\), and it is thought that there are over 100,000 young carers in Scotland.\(^2\)

3.2 There is someone caring in 14% of households – although the SHS 2007-8 estimates that more than 33% of households contain someone with an illness, disability or long term condition. It is therefore likely that carer figures in Scotland are greater. Seventy percent of carers have been providing care for more than five years.\(^3\)

3.3 Carers are the largest source of care and support in Scotland and are therefore a critical element underpinning the delivery of health and social care services in Scotland. It would cost over £10.3 billion annually to replace the care they provide - roughly equivalent to the NHS budget in Scotland. As we continue to face substantial financial

---
\(^1\) Scottish Household Survey, 2007/08
\(^2\) Scottish Government/Minister for Public Health 2008
\(^3\) Scottish Household Survey 2007/08
challenges as a nation, it makes good fiscal sense to provide support to these people who effectively prevent the collapse of health and social care – support which enables them to continue caring.

3.4 Despite this contribution, carers tell us time and time again that they feel “unrecognized” and still find it difficult to access support in their own right. Many talk about the stress of managing the ‘bureaucracy of caring’ and of having to navigate through a system which often doesn’t make it easy to do so. Research/evaluations indicate that access to information and tailored support, financial advice and breaks in caring are vital in helping them manage the impact of caring on their health and financial wellbeing and on their day to day lives. Carers also tell us that without that support, statutory services are far more likely to have to intervene as a result of more costly crisis situations.

The Change Fund attached to the Reshaping Care agenda recognises this, and indeed the contribution carers can make has been further acknowledged in the commitment to ensure that 20% of the Change Fund should be focussed on supporting unpaid carers who look after older people, including older carers themselves. This commitment is reiterated within the Draft Budget, but we retain some concern as to how the impact of the fund might be evaluated.

3.5 Whilst 250,000 carers balance both employment and caring for a relative or friend 4 caring directly impacts on employment and economic activity. A recent survey of more than 700 carers across the UK indicated that nearly 60% of carers had given up paid work to look after a sick or disabled relative. More than half of those who did still work earned less than £10,000.5 Where people care for more than 20 hours per week, they are more likely to be in part time employment or unemployed.6 Additional pressures and demands on this group arise directly from cuts to health and social care spending which could mean that many may need to give up their jobs to care. This would represent a huge loss of skills and talents to the labour market – the bulk of carers are in their 40s/50s and are therefore at the peak of their careers.

The reality is that many unpaid carers reduce their hours of work or move into jobs which do not reflect their experience or qualifications in order to manage caring and employment. This has a substantial impact on earnings, future earnings and the ability to build up a pension or savings leading to increased poverty now and in future.7 Notwithstanding the significant personal cost of giving up work to care, loss of employment also has a hard economic cost, with reduced tax receipts and national insurance, increased welfare costs and less family income to spend in local communities. Multiplied across the

---

4 Carers Scotland
5 Broke and Broken – The Princess Royal Trust for Carers 2010
6 Census 2001
7 Out of Pocket (2007), Carers UK
number of carers who give up work to care, these reductions can be significant.

3.6 In turn, unpaid carers and young carers are more likely to experience poverty and the problems associated with this. Carers are the biggest social group experiencing fuel poverty (two thirds of carers) with many also cutting back on heating and other essentials in order just to live from day to day. Essential medical equipment such as suction machines needs to be on or charged 24/7. As a result, families tell us that they are increasingly worried about how they will afford to keep paying fuel bills this winter.

3.7 The changing demography of Scotland means that we will need far more carers in future – some 1 million by 2037. Caring will affect almost everyone. As policies to ‘shift the balance of care’ are implemented, there is a real risk that the burden already sustained by carers and young carers will increase with a subsequent impact on ability to sustain, move into or progress within employment.

The recent recognition of unpaid carers and young carers within the newly refreshed Skills for Scotland Strategy ensures a strategic focus on the skills development and employability needs of this group. This needs to be taken forward, with key agencies and learning providers recognising them as a target group. It was disappointing that the recently refreshed Economic Strategy does not recognise the contribution made by unpaid carers.

As the caring journey comes to an end, carers and young carers may also need support to look at the new life and opportunities open to them, particularly where they have been caring intensely for a number of months/years.

3.8 Lastly, unpaid carers and young carers are more likely to suffer poor physical and mental health, particularly those who are providing intensive levels of care. This affects their ability to care, which in turn can place additional pressure on statutory services. A recent survey of older carers, aged 60-94, showed that 65% have long term health problems or a disability themselves and seven out of ten (68.8%) say that being a carer has an adverse effect on their mental health. The pressures of caring also particularly affect older carers in other ways; a major concern for eight out of ten is what will happen to the person they care for in the future, whilst only half feel safe or confident in lifting the person they care for.

---

8 Carers UK, 2008
11 Carers UK 2008
12 Always on Call, Always Concerned – The Princess Royal Trust for Carers, 2011
4. **Spend to Save - Support for Unpaid Carers and Young Carers as Prevention**

4.1 The nature and scale of the support that unpaid carers provide along with the substantial challenges that they continue to face, mean that they should be seen as a key group requiring preventative investment across statutory and voluntary services. The Scottish Government itself recognises this in the new Scottish Carers’ Strategy:

“Providing support to carers makes *economic sense* by saving resources in the longer term. With appropriate and timely support carers are able to care for longer, and enjoy better health and improved well-being. Carers do not usually 'down tools,' but unsupported they can experience real hardship financially, physically and emotionally. It is much more likely that a cared-for person will be admitted to hospital and the carer’s own health deteriorates if the carer is unsupported. Carers can easily reach crisis point without *appropriate and timely intervention*. Such interventions can:

- Maintain carers’ capacity, reducing the need for paid service delivery to the cared-for person; and
- Help keep carers healthy, reducing their own need for support from the health and the social care system.”

4.2 **Timely support for carers generates savings to statutory services**

Having an unpaid carer in place, and providing support to carers and young carers in their own right can improve outcomes for patients, and can reduce costly emergency and re-admissions to hospitals and to residential care. Please find in Appendix 2 a link to a report called “The Case for Change”\(^\text{14}\). Published by The Princess Royal Trust for Carers this year, it highlights a range of evidence which demonstrates that supporting carers through Carers’ Centres and other means involving early intervention/preventative approaches can save money for local authorities and health services. For example:

- The care and support provided by unpaid carers directly impacts on health outcomes for people with care and support needs. Research looking at training for unpaid carers supporting stroke patients demonstrated earlier independence for the patient and a reduced requirement for physiotherapy and occupational therapy.

- Supporting carers to maintain their own health and wellbeing reduces their need for statutory interventions; they are also able to continue caring which reduces the need for statutory services for the cared for individual.


\(^{14}\) Supporting Carers: The Case for Change, The Princess Royal Trust for Carers, 2011
Supporting carers can help improve outcomes from personalisation; carers cite training and access to support and advice as important in managing a personal budget. This has implications for the Self Directed Support Bill which is due to move through Parliament this session.

Carer support can reduce residential care admissions (longitudinal study of institutionalisation in people with dementia); supporting carers can further reduce admissions as carer stress in one study was the reason for admission in over one third of cases.

Carers receiving low level support in a US study stayed at home for longer (and therefore continued caring) than carers who were not supported.

Supporting carers can reduce hospital bed stays; a whole systems study tracking a sample of older people (aged over 75 years) who had entered the health/social care system found that 20% were admitted to hospital because of a breakdown in the caring situation where the individual was dependent on a lone unpaid carer.

Improved discharge processes involving carers directly and training carers prior to discharge (stroke patients) reduced hospital costs in a UK trial (from an average of £13,794 to £10,133).

Respite and short breaks from caring are critical for unpaid carers. They have a clear preventative focus in terms of keeping families together and preventing carers’ own health from breaking down.

Even with current policy initiatives, guidance and additional investment (at least £3 million in 2011/12) from the Scottish Government, access to good quality respite and short breaks is still a real concern for carers. Feedback from different parts of the country suggests that eligibility criteria for short breaks are being tightened with support only being provided when families or carers reach breaking point – often too late.

Carers are less likely to suffer from poor mental health if they are able to take a break from caring. For some groups, however - e.g. those supporting family members with mental ill health or substance misuse issues - access to an appropriate short break is virtually impossible.

New technology including telecare and telehealth solutions can help complement and support the care that unpaid carers provide. Modest investments can offer significant positive benefits to carers’ own health and wellbeing. Research published by Carers’ Scotland

---

15 Partners in Care, The Princess Royal Trust for Carers, GSK and Q2 Research (2004)
identified a range of benefits including greater peace of mind, less stress and worry, more opportunity to have a break from caring and getting a better night’s sleep.

- The emotional and health impacts of caring for family members who are ill or suffer from a disability are increasingly recognised e.g. “Building a Health Service Fit for the Future” 17 and Care 21.18 Without effective support, carers’ health can suffer directly; they are more likely to suffer from anxiety and depression; they are more likely to be admitted to hospital or to receive medication and other health interventions which in turn can reduce their ability to care. There are clear cost implications as a result – the costs of a carer needing hospital treatment are multiplied as the person they care for will also need increased NHS and social care support.

4.3 Carer Support: Investing to Save

A recent Social Return on Investment (SROI) study completed on five Carers’ Centres in England estimated that an investment of less than £5 million in services provided by the Centres resulted in at least £73 million worth of social gains in a year. Across the UK, that return would be around £800 million. There are 29 Carers Centres in Scotland which receive around £5 m investment each year from a range of sources – the SROI analysis will be translated to the Scottish context over the next 5 months.

4.4 Enabling Young Carers to Achieve Their Potential

Evidence demonstrates that investment in specialist young carers’ services to support young carers (generally from the ages of 7 or 8 up to 18 years of age) can generate cost savings to the tune of £6.72 for every £1 of core funding.19 Yet, funding for many young carers’ services ends at 18 – a key point of transition for young people – increasingly so as young people remain on at school for longer in the current difficult economic climate.20

The impact of caring on transitions from school was recognised in “More Choices, More Chances” with young carers identified as a target group for early intervention.21

The outcomes that young people experience, their own health and achievements are affected when having to live with family members affected by substance misuse. Approximately 40,000 to 60,000 children are affected.22. Early intervention in the lives of these young people is

---

18 http://www.scotland.gov.uk/Publications/2006/02/28094157/50
19 At What Cost to Young Carers? Crossroads Caring and The Princess Royal Trust for Carers of Caregivers 2008
21 More Choices, More Chances, Scottish Executive, 2006
22 The Road to Recovery, Scottish Government, 2008
deemed to be important in ensuring the best possible outcomes for them. Many will fall into the 'looked after and accommodated' category of young people and consistently, these young people have much poorer educational outcomes than their peers – the 2008/09 School Leaver Destination Return demonstrated that only 2.6% of looked after children moved into Higher Education on leaving school compared with 35.5% of all other children in the cohort.

Young carers' services have a key role here, in the wider context of the support infrastructure for these vulnerable young people and yet funding challenges mean that young carers’ projects can only reach and support just over 3,000 children and young people each year.

5. Carer Support in Scotland and the Draft Budget/Spending Review

5.1 The last administration presided over a marked change of attitude and approach to both recognising and supporting unpaid carers in Scotland. Implementation of Carer Information Strategies with linked funding, commitments to directly fund voluntary organisations to provide respite and to carers’ organisations to provide, e.g. carer training have been widely welcomed by carers and representative organisations and have positively impacted on the lives of carers and young carers across the country.

5.2 The Budget for 2011/12 committed to continuation of Carer Information Strategy funding and further support to develop and build on existing carer training across the country. Already this year, as a result of clearer guidance to health boards, local Carers Centres will be able to expand their support in local communities.

5.3 The introduction of the Change Fund is the most significant investment to date to recognise the value of identifying and supporting unpaid carers. An election manifesto commitment to allocate 20% of this (some £40+m) to supporting carers to continue caring acknowledges their significant contribution to statutory services in Scotland. The Draft Budget for 2012 and Spending Review retain this commitment. There is also a commitment to “ring-fence support for carers, implementing the commitments in our Carers and Young Carers' Strategy”. Whilst this latter statement most likely refers to the continued strand of Carer Information Strategy funding and commitments to provide monies to voluntary organisations for respite and short breaks for unpaid carers and their families, it is nevertheless extremely welcome and ensures a clearer line of sight between national intention and local delivery.

5.4 There is however a risk attached with such investment; as local authorities seek to make cuts at local level, the core funding which enables local carer organisations harness external funding could be at risk.

23 As above - http://www.scotland.gov.uk/Publications/2008/05/22161610/7
5.5 Our concerns lie with the ongoing implementation of the Change Fund for ‘Reshaping Care’. The commitment to ensure that at least 20% of the Fund will be dedicated from 2012 to helping carers to continue to care is a hugely positive step, representing up to £46 million which could be directly used to impact positively on the lives of Scotland’s unpaid carers, particularly older carers and those who support older relatives/friends. Anecdotally however, feedback tells us that in some localities, there is can be little recognition of the impact of Reshaping Care on families, and that bids to local Change Funds do not always recognise the need to build in support to carers who provide the bulk of care in Scotland. Very few carers’ organisations which hold local expertise and knowledge on how to identify and support unpaid carers have been able to get to the table to influence Change Fund Plans or indeed access funding to help them meet potentially increased demand for carer support. What is perhaps more worrying is that many localities have already notionally allocated Change Fund monies for the next three years and will need to substantially revisit their plans to take account of the 20% commitment.

5.6 Planned guidance to support the implementation of the Change Fund must be strong and direct local partners to actively involve local carers’ organisations and carers at both strategic and operational levels, and ensure that the organisations which can best contribute to outcomes which impact on unpaid carers are key players.

5.7 We would ask the Health Committee to consider how this current tranche of Change Fund money is being allocated, and how its outcomes for carers and older people will be evaluated.

Lynn Williams, The Princess Royal Trust for Carers
Fiona Collie, Carers Scotland

18 October 2011
Appendix 1

Carer Support in Scotland
The Princess Royal Trust for Carers, Carers’ Centres offer

Last year, Carers Centres worked with over 54,000 carers and young carers – up almost 10% on 2009/10.

Each Centre offers a range of core services which seek to maximise the health, wellbeing and life chances of unpaid carers and young carers across the country.

These services include:

- **Information & Advice** – based on a solid understanding of the needs of each carer and those they care for. Centres are grounded in their local communities and have a strong network of statutory and other partners.

- **Income Maximisation** – All carers are offered a comprehensive welfare benefits checks and support to access a range of other grants/trusts. This money is invested back into local communities through carers’ spending. The four Princess Royal Trust for Carers’ Centres in Glasgow secured £1.6 million for carers, young carers and their families which was spent in local communities in 2009/10.

- **Emotional Support & Carer Support Groups** – Emotional support is critical to carer wellbeing and health and in helping carers to continue caring. Carers are supported on a one to one basis or within carer support groups.

- **Training and Learning for Carers** – Carers are offered a range of training and learning opportunities which impact positively on health and wellbeing and enable carers to keep their skills up to date whilst helping them to maintain their caring role.

- **Promoting Carer/Young Carer Life Chances: Education, Training & Employment** - Centres will support and encourage carers to explore new lifelong learning opportunities. For carers who are already in employment, Centres support them to understand the options open to them around balancing care and employment and help those who can to sustain work whilst caring.

- **Access to Short Breaks** - Centres help carers and young carers access a tailored and effective short break from their caring role. Some of the Centres in the Network have access to their own short breaks budget and have recently benefitted from the additional monies made available to voluntary organisations from the Scottish Government for respite/short breaks.

Centres also provide or can help carers access advocacy to help have their voice heard and to access the right services for them and their families.

Nationally, the Centres have access to support around issues such as policy, quality assurance and access to additional funds as a result of being part of the Network of Carers’ Centres in Scotland and UK wide.
Supporting Carers: The Case for Change

Some information on and a link to this report can be found at: