

# **A capacity review of local carer organisations to inform the 2007 Spending Review - January 2007**

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## Section One

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### 1.1 Introduction

There are 480,000<sup>1</sup> unpaid carers in Scotland who save the government £5.3 billion pounds every year, equivalent to more than half of the entire budget of NHS Scotland. Of these, 115,000 care full time, without pay, for over 50 hours a week. 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.

One in five carers suffer from poor health and they are a third more likely to become permanently sick or disabled than non-carers.<sup>2</sup> When carers are forced to give up caring due to poor health, the cost of replacement care is passed on to statutory services. While the costs of supporting carers are modest, the cost of providing full time replacement care is approximately £28,000 a year per person. If just five carers out of every 100 were unable to care, Scotland's public services would be faced with an additional bill of over £280 million a year.

It has become increasingly clear that we need to invest in carer services in order to support and sustain the carer population. Consideration must be given to carer's own health needs, with early identification of carers leading to access to dedicated carer services. The outcomes from this investment will include:

- better health and wellbeing for carers,
- a better quality of life for both carers and the people they care for,
- measurable economic benefits resulting from fewer admissions to hospital and long-term care.
- reduced cost of patient care

Commissioned by the Scottish Executive, the Care 21 Report '*The Future of Unpaid Care in Scotland*' sets forward a bold vision where carers are included in a society in which their contribution is fully recognised and properly supported. This is a 10 year plan, with the initial priorities being young carers, respite for carers, carers health and carer training. In the Executive's response to the report there was also recognition of the important role played by local carer support organisations. Recommendation 18 states:

*'We recommend that Scotland's existing network of local carer support organisations is strengthened'*

The Executive acknowledged the need to review the capacity of local carers support organisations. It showed commitment to strengthening and investing in the network by setting an early priority to be considered within the spending review:

*'The Executive acknowledges the important role of voluntary sector carer centres in delivering effective local carer support, and in supporting health and social care services to deliver national objectives. We will review capacity with the help of*

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<sup>1</sup> Figures are taken from the 2001 census. More recent research undertaken by the Scottish Household Survey 2003-2004 identified 660,000 unpaid carers, but does not provide any further breakdown of figures.

<sup>2</sup> Information taken from the report 'In Poor Health. The impact of caring on health' published by Carers UK, 2004.

*Princess Royal Trust Scotland and the Coalition of Carers in Scotland to inform consideration of this recommendation in the 2007 Spending Review.'*

This report seeks to inform that process by evidencing the need for further investment in the following key areas of carers support:

- information and advice
- emotional support
- carer training
- advocacy

We will outline the key policy drivers which make this a priority within current social care and health reform. We will provide details of current service provision within Scotland and its future capacity. Finally, we will put forward a compelling argument for the need for additional investment.

## **1.2 Current Capacity of Local Carer Organisations in Scotland**

At present there are 29 Princess Royal Trust Carers Centres in Scotland, as well as over 20 local carer organisations who are not affiliated to the network. In addition, several national disability organisations, such as Alzheimers Scotland – Action on Dementia and NSF Scotland, provide support services to carers. There are dedicated carer support services in every local authority, with the exception of the Western Isles, Shetland and two communities within Argyll and Bute.

Local carer organisations based within the voluntary sector provide a range of emotional and practical support services to carers. Nearly all provide an information and advice service and emotional support services such as a listening ear and peer support groups. Many provide additional services including:

- income maximisation
- respite and short break services
- carer training opportunities
- counselling services
- advocacy services
- employment advice services
- volunteering services
- services for young carers
- services for specific groups such as young carers, carers from an ethnic minority, parent carers, carers looking after someone with a mental illness and carers of people who are dependent on drugs or alcohol

The Princess Royal Trust network of Carers Centres is currently in contact with 50,000 carers and they identify an additional 6,000 new carers every year. While it is difficult to estimate how many carers are supported through other carer support organisations we know that the smaller organisations support approx 100 to 150 carers, while the larger organisations support up to 1,500 carers. We can therefore estimate that the figure is at least an additional 8,500 carers.

The funding of local carer organisations varies considerably in both the amount of funding received and the sources of funding. Some carer organisations have substantial core funding through their local authority, such as Dumfries and Galloway which has an annual grant of £156,927 from their local authority and covers a

population area of 147,765 with an estimated population of 14,038 carers. As well as providing stability, core funding is essential to lever in additional funds for service development.

Other carer organisations struggle to maintain their current level of services since they do not have adequate or secure core funding. For example North Argyll Carers Centre has an annual grant of £30,000 from their local authority and covers a population area of 22,000 with an estimated population of 2,750 carers. They have an annual deficit of £100,000 which requires them to divert much of their energy into fundraising to maintain their core services.

Some carer organisations rely entirely on local fundraising efforts and grants from charities, such as the lottery. For example, the Carers Support Service in Lochgilphead does not receive any local authority funding. It is run entirely by volunteers and is the only dedicated carer support service in Bute and Cowall

In the last year many local carer organisations have seen a sharp increase in the number of carers referred to their services. This can be attributed to the rights and recognition carers have been awarded in recent policy and legislation and the increased profile of carers resulting from successful media campaigns.

Emerging evidence from the network of Princess Royal Trust Carers Centres shows that the number of referrals from health services has increased by over 100% from April to September 2006, compared to the period September to March 2006.

This trend is set to increase with the GMS contract and NHS Carer Information Strategies both introducing new responsibilities on health services to identify carers and signpost them to their local carer support organisation. The NHS Carer Information Strategies are due to be implemented in April 2007 and this should result in carers being systematically identified and referred to their local carer support service.

Local carer organisations currently provide a service to 12% of the carer population. As more carers are provided with information about carer support services, inevitably referrals to these organisations are set to increase. Organisations with limited resources are already struggling to provide a service to those carers they are currently in contact with and even organisations with substantial funding from their local authority would be unable to cope with a significant increase in referrals, without a corresponding increase in resources.

### **1.3 Summary of Recommendations**

These recommendations reflect the rights and entitlements outlined in Scotland's Carers Manifesto 2007, which was jointly produced by the National Carer Organisations.<sup>3</sup> They are based on strong evidence which details the benefits of these services to carers, the current provision in Scotland and the need for additional investment to support the future capacity of local carer support organisations. A detailed report of each recommendation may be found in Section Two (below)

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<sup>3</sup> The following organisations are members of the National Carer Organisations Group – Carers Scotland, The Coalition of Carers in Scotland, Crossroads Scotland, The Princess Royal Trust for Carers, Shared Care Scotland and the Young Carers Alliance.

- Information and Advice services require an investment of £1,540,000
  - This will fund an additional 44 information and advice workers to address the increase in referrals resulting from the GMS contract and the impact of local NHS Carer Information Strategies.
  - This will provide a service to an additional 8,800 carers per annum.
  
- Emotional Support Services require an investment of £1.5 million
  - This will fund emotional support services for an additional 3,500 carers in Scotland
  - This will ensure at least 1000 carers benefit from personal counselling support each year
  - This will fund 300 carer support groups in Scotland, each providing a service to up to 12 carers
  
- Carer Training Services require an investment of £1.824,000
  - This will ensure that at least 4,000 carers have the opportunity to participate in an 'expert carer' training programme each year
  - This will provide resources for 14 carer training partnerships linked to local NHS Boards
  - This will fund 32 carer training posts to assist in the co-ordination and delivery of 'expert carer' training courses
  
- Carer Advocacy Services require an investment of £3 million
  - This will provide dedicated advocacy support to 6,200 carers per annum
  - This will fund 75 carer advocacy posts and support 200 volunteer advocates.

## **Section Two**

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### **Information and Advice**

#### **2.1 Introduction**

*Unpaid carers require appropriate information and advice at every level of the caring journey. They prefer information directly from NHS contact points or from 'one-stop shops' such as local Carer Centres, rather than having to piece together information from a wide range of sources and agencies' (The Kerr Report – 'Building a Health Service Fit for the Future')*

High quality, accessible, information and advice services for carers are the foundation on which all other carer support services are based. They empower carers by giving them the tools to make choices about their caring situation. They assist carers in developing vital support mechanisms which allow them to sustain their caring role and they promote good health and wellbeing by facilitating early access to support services and preventing crisis management.

Dedicated information and advice services provided through local carer organisations are able to use their specialist knowledge and expertise to deliver a holistic approach to information provision. This promotes access to carer's assessments, income maximisation services, carers support services, as well as services for the cared-for person. Services are designed specifically for the needs of carers, which enables them to establish long-term trusting relationships with carers. The Care 21 'Voices of Carers' research found that 75% of carers surveyed named a local carer organisation as their source of support, only 9% identified social work and 4% identified health in this role. Similarly 60% of carers who had been informed of their right to a carers assessment had been informed through their local carer organisation.

#### **2.2 Policy Context**

The provision of information and advice to carers is a key priority within the Care 21 report '*The Future of Unpaid Care in Scotland.*' It is integral to the successful implementation of many of the 22 recommendations, as well as being the direct focus of recommendation five:

*'We recommend that all frontline staff with direct responsibilities for supporting the needs of carers in 'first contact' organisations (local authorities, health and voluntary organisations) are properly equipped to advise unpaid carer about their rights, entitlements and available services'*

In responding to this recommendation the Executive stated:

*'We support pro-active and targeted provision of information to carers and believe that this is best achieved by effective partnership working across the statutory and voluntary sectors'*

Partnership working, is also a central theme in the delivery of NHS Carer Information Strategies, with local carer organisations playing a key role in information provision: *'Where strategies work well, carers will be identified early on in their caring role. They will then be signposted to local advice, usually voluntary sector carer centres. That way carers will be systematically made aware of their rights as well as a range of practical support services'*

Both The Kerr Report - ' *Building a Health Service Fit for the Future* ' and the 21<sup>st</sup> Century Social Work Review ' *Changing Lives* ' identify the need for greater involvement from patients/clients and carers in the design and delivery of services. They also recognise the vital role that carers play in contributing to the delivery of health and social care services.

*'Managing growing demand for services means that we need to develop the capacity of individuals, families and communities to find solutions to their own problems. This will be done by building on strengths and skills, promoting resilience and strengthening informal support networks'.*

There is an acknowledgement that for these new models of care to be successful, information, advice and support must be made available to both patients/clients and carers. If this is not achieved it will result in a greater burden of care being placed on carers with a resulting negative effect on both their own health and wellbeing and the health and wellbeing of the people they care for.

### **2.3 Current Provision**

In the last financial year the Princess Royal Trust network received over 57,000 carer enquiries and provided a service to over 6,000 new carers. Yet the network has only 44 information and advice workers. Similarly, local carer organisations who are not part of this network and also national disability charities who offer a dedicated carer support service, also have a high proportion of carer enquiries per staff member. Overall, carer information workers working within the voluntary sector carry a much higher caseload than their counterparts working within local authority services.

Most local carer organisations are struggling to cope with the increasing numbers of referrals they are receiving from partner organisations, with the biggest increases coming from health. They also have a commitment to continue to provide an ongoing service to more than 58,500 adult carers who are in contact with local carer organisations across Scotland. Yet this only represents 12% of the overall carer population. Investment is required to increase the capacity of local carer organisations, by funding additional staff posts.

### **2.4 Investment Proposal**

We propose that £1.540,000 is invested in information and advice services for carers, in order to fund an additional 44 staff posts with a specific remit to provide information, advice and income maximisation services to carers. This will almost double the capacity of the local carer organisations in relation to information and advice provision, providing a service to an additional 8,800 carers per annum. This investment will ensure that organisations are able to adequately respond to the increasing numbers of carers referred to their services.

## Emotional Support

### 2.5 Introduction

*“The ability of thousands of unpaid family carers to cope with their role as care providers depends on managing the emotional impact of impairment, illness and caring. Impairment and illness often have significant impacts on ‘natural’ relationships between people and their life expectations. Frustration, anger, guilt, depression and a sense of hopelessness mix with desires to provide the best possible quality of life for people with support needs and their families.*

*The impact of impairment and illness on the mental and emotional health of carers, siblings and other family members is increasingly well documented. Planned support for unpaid carers should include the provision of emotional support, counselling, peer group support and mentoring.*

*As with training programmes on the practical aspects of caring, NHS investment and support of emotional support programmes and facilities would provide a significant resource to support carers to cope positively with their role.”<sup>4</sup>*

The emotional impact of caring is well documented, as is the benefit of emotional support to help carers cope with changing relationships. This is particularly true for carers in long-term caring situations with complex and intensive caring responsibilities, be it as a result of accident, disability, addiction or terminal illness.

Carers from all caring situations report significant benefits from individual and peer support which allows them to address deeply sensitive and personal issues. This is evidenced by carers’ testaments in the Care 21 report “The Future of Unpaid Care in Scotland”, Appendix 4: Voices of Carers II, Section 3.9: Carers’ health: psychological and emotional support.

Despite growing recognition, emotional support for carers is still widely neglected and often remains a taboo. Traditional community care support focuses more on alleviating physical challenges and caring tasks with aids, adaptations or professional care support, but largely neglects the needs of families and carers to understand and manage the emotional aspects of changing relationships, guilt and frustration, or the feelings of loss which accompany many caring situations.

### 2.6 Policy context

First recognised by government in ‘Caring About Carers’, the UK Carer Strategy published in 1999, the need for emotional support for carers has increasingly been highlighted in relevant research and policy developments since.

Among numerous references to the emotional impact of caring, the 1999 Strategy states “Emotional support may best be met ... in more organised ways such as through support groups. Skilled help at particular times – for example near the start of caring or if the condition of the person being cared for changes – can be of

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<sup>4</sup> Extract from ‘Building a Health Service Fit for the Future. A National Framework for Service Change in the NHS in Scotland.’ Volume 2: A guide for the NHS

considerable assistance to the carer. Recent research suggests that it may result in an increased ability to continue to care.”

The 1999 strategy also recognises the important connection between the emotional and mental health of a carer and their ability to care: “Emotional support may just mean having someone to listen to problems. It may mean help and advice from someone else who is or who has been a carer. Mental and emotional wellbeing can also result from feeling in control of the situation – which means, for carers, having the information to help them to care. Not all carers will want to join a support group or will find it helpful, but research suggests that carers who have links with a support group are better able to continue to provide care.”

Care 21 headline report “The Future of Unpaid Care in Scotland” (2005) acknowledges the need for counselling and psychological support. It recommends that “increased access to counselling and emotional support services is made available to unpaid carers”. This recommendation is based on evidence from “... previous research that many carers experience periods of isolation and/ or stress, which may result in a depressive illness as a result of their caring situation. This research has corroborated existing research and has also uncovered the physical and mental impact of ill-health associated with the unpaid care task. This can be exemplified in the physical strain associated with moving and handling, as well as the emotional impact of caring and resultant social isolation.”

The Scottish Executive’s response to “The Future of Unpaid Care in Scotland” sets out the need for strategic initiatives to support unpaid family carers, and has prioritised action on carers’ health, including emotional and psychological support for the intensive work they do.

## **2.7 Current Provision**

Access to emotional support is a vital aspect of caring support and many local carer organisations seek to provide emotional support in the form of a listening ear or carer support groups. Stress management classes are increasingly popular with carers.

However, specific counselling and groupwork services provided by professional counsellors and facilitators are rare. Emotional support – ranging from facilitated care-specific support groups to small groupwork and peer support and individual counselling – is under-resourced, fragmented, and in many parts of Scotland non-existent.

Where good practice exists it is often provided with short-term funding by lottery or trust fund grants. In Edinburgh, a dedicated carer counselling service draws on ten professional volunteer counsellors to support over 70 carers every year with a further 100 carers benefiting from small peer and groupwork sessions dealing with changing relationships, guilt, and loss. It is the only known area in Scotland where professional carer counselling and peer groupwork are supported by local authority or NHS grants (a carer strategy grant of £10,000 funds 30% of the service cost).

## **2.8 Investment Proposal**

This proposal sets out a target of providing appropriate emotional support to at least 3% of those carers who care for 50 hours or more a week. This will benefit 3,500 carers in Scotland (of a total of 115,000 who provide 50+ hours care).

£1.5 million investment is required to increase local capacity for the provision of emotional support. This focuses on four specific areas of professional carer support:

- one-to-one counselling services for carers which will work to the BACP (British Association for Counselling and Psychotherapy) “Ethical Framework of Good Practice”
- and/or the COSCA (Confederation of Scottish Counselling Agencies) “Statement of Ethics and Code of Practice”;
- professional telephone support for carers, particularly those in rural and remote areas. This may be in the form of a telephone counselling service where counsellor and carer set up regular counselling sessions over the phone, or a more occasional service where a carer support worker provides a listening ear (i.e. uses counselling skills but without formal counselling contract with the carer)
- peer groupwork programmes for small groups of carers sharing similar issues; and
- facilitated carer support groups;
- dedicated mentoring or life-coaching classes

### **Individual Counselling & Telephone Support**

£600,000 is required to establish access to individual counselling support in every area of Scotland and ensure at least 1,000 carers benefit from personal counselling support each year. This would cover approx 1% of the total number of most involved carers, i.e. those currently caring for 50 hours or more a week (*Census 2001*).

Directed via NHS Boards or local authorities, such provision would vary from rural to urban areas, and may include both time-limited or longer-term services. Appropriate forms of provision, including telephone support, will be developed within localities, to ensure equitable quality standards and provision across the country.

### **Groupwork Support**

£300,000 is required to facilitate local programmes of groupwork courses to address emotional aspects of caring in small peer groups. This would include 500 one-day sessions for up to 3,000 carers a year, provided by professional counsellors or psychotherapists.

### **Carer Support Groups**

£600,000 is required to resource 300 carer support groups across the country per year, each for a duration of 24 months, consisting on average of up to 12 members. Carer support groups will be managed by professional facilitators, but are more self-directive in the peer support they provide than specific groupwork programmes above.

Access to such funding should be open to local carer centres and carer support organisations, and to national and local long-term condition agencies such as Parkinson's, NSF Scotland, Chest, Heart & Stroke, etc.

## **National guidelines and service criteria**

To ensure equitable access to high quality support services across the country, funding allocations should be subject to meeting national guidelines on professional criteria and quality standards. To ensure equity of access, consideration should also be given to the cultural needs of carers from BME communities and other hard-to-reach groups.

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## **Training for Carers**

### **2.9 Introduction**

In recent years the perception of unpaid carers as the passive recipients of services has changed. It is now recognised that carers are partners in the provision of care who require support and training to equip them for their caring role.

In the largest carer study undertaken in Scotland nearly 3,000 of 4,267 carers surveyed (70%) reported that their caring role includes personal and medical care. (Care 21 report "The Future of Unpaid Care in Scotland"). Yet two thirds of carers who provide medical care have not received any training or guidance on medication, dressings or injections. And while Scotland's health care workforce are trained in moving and lifting patients safely, only 3% of carers have received the same training.

Carer training results in a better quality of life for the carer and the person they care for. Benefits for carers include increased knowledge and confidence, improved health and wellbeing and fewer injuries relating to their caring role. Furthermore, there are tangible economic savings from reduced NHS and social care interventions, fewer hospital admissions and a lower incidence of the caring role breaking down.

A recent study published in the British Medical Journal in May 2004 examined the effectiveness of training carers in reducing the burden of stroke for both patients and their unpaid carers. It concluded that, as well as reducing the cost of patient care by £3,500 per patient per year, both the carer and patient reported less anxiety, fewer incidents of depression and a higher quality of life.<sup>5</sup>

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<sup>5</sup> 'Training carers of stroke patients: randomised control trial' Kalra et al (BMJ 2004;328;1099)

## 2.10 Policy Context

Carer training has been identified as a priority within the Care 21 report '*The Future of Unpaid Care in Scotland*'.<sup>6</sup> The Executive recognises that the overall picture of provision within Scotland is '*varied and patchy*' and acknowledges the need for a national 'expert carer' training framework. The Executive has agreed to '*consider the recommendation for an expansion of carer training in next year's spending review*'.

In The Kerr Report – '*Building a Health Service Fit for the Future*',<sup>7</sup> carers are recognised as playing a vital role as partners in care in the move towards a more preventative and proactive model of care. The report acknowledges the effect caring can have on the carer's own health and recommends that the NHS should develop and provide carer training: '*so that carers can maintain their own health and wellbeing and maximise their contribution to the health and wellbeing of the person they care for*'.

This recommendation has been further strengthened through the recent guidance relating to the development of NHS Carer Information Strategies.<sup>8</sup> This places a new responsibility on health boards to demonstrate that carers have access to key training opportunities including moving and lifting techniques, advice on stress management and physical and emotional wellbeing and information on specific conditions. They must also: '*Identify proposals for the development of a strategic approach to 'expert carer' training, aimed directly at supporting carers in their caring role and targeted specifically at carers with intensive, or potentially growing, caring responsibilities*'.

## 2.11 Current Provision

A recent study undertaken by The Coalition of Carers in Scotland and The Princess Royal Trust for Carers for the Scottish Executive Carer Policy Branch, investigated current provision of training opportunities for carers in Scotland.<sup>9</sup> The report found that, while a variety of courses are available to carers in many areas, funding is varied and piecemeal and carers have no access to training opportunities in three areas.

Training is provided mainly by local and national carer organisations, frequently in partnership with other organisations. Carer organisations expressed concerns at the instability of their funding arrangements with 19% of respondents saying they had no dedicated funding for training, while a further 30% received only partial funding from a dedicated source.

The areas with no training resources are: the Western Isles, Shetland and parts of Argyll and Bute. Of these areas, none had a Carers Centre or organisation which provided information and support specifically to carers. In addition, 19 local

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<sup>6</sup> '*The Future of Unpaid Care in Scotland*' Care 21, OPM (February 2006)

<sup>7</sup> '*Building a Health Service Fit for the Future*' A National Framework for Service Change in the NHS in Scotland, The Scottish Executive (May 2005)

<sup>8</sup> 'HLD22/2006 NHS Carer Information Strategies: minimum requirements and guidance on implementation' The Scottish Executive (April 2006)

<sup>9</sup> '*A Study of Training for Carers in Scotland*' COCIS, PRTC (August 2006)

organisations out of the 29 who contributed to the study identified demand for courses which they were unable to meet. Demand was mainly for moving and lifting and other practical training relating to caring tasks.

The carers who contributed their views to the survey were unanimous in prioritising the need for training opportunities aimed at developing their caring skills, knowledge and expertise. Those who had participated in training courses acknowledged the 'huge benefits' this had brought them. They also confirmed the importance of easy access and flexibility, so that training can be fitted around their caring responsibilities and can be accessed when needed, often in anticipation of changes in their caring situation

## 2.12 Investment Proposal

Strategic investment in training for carers is recommended to ensure availability across Scotland of key training subjects related to caring tasks, to redress the unevenness of funding between areas and thereby the uncertainty of what is recognised as a vital element in health-care strategy.

As an initial investment, £1.82 million a year is needed to successfully establish local carer training partnerships involving all relevant agencies, and the development of 'Expert Carer' training programmes across all local and health authorities in Scotland to deliver training to at least 4,000 carers every year. These training programmes will allow carers to develop their own skills, knowledge and expertise in areas which have been traditionally viewed as the domain of 'professionals'.

'Expert Carer' training programmes will be targeted to carers with intensive care management tasks and those likely to care for many years. They will form part of the Executive's commitment to develop long term condition management strategies to reduce hospital admissions and further shift the balance of care.

Investment of £1.82 million will fund local Carers Training Co-ordinators and the delivery of 'expert carer' training to 4,000 carers across Scotland per year. In line with recommendations outlined in the Care 21 report, priority will be given to carers of people with long term conditions, and carers likely to provide intensive and long-term care. The programme will be free to carers and alternative care arrangements will be provided where appropriate. Consideration will also be given to the cultural needs of carers from BME communities and the needs of carers with communication issues. Appropriate training material will also be developed to meet the needs of young carers.

<b>Expert Carer Training Programme</b>		<b>£</b>
<b>LOCAL COSTS</b>		
14 Carer training Partnerships	1 per NHS Board @ £2000 p.a.	28,000
32 Training Co-ordination/Delivery Posts	1 per LA area at £30,000 p.a.	960,000
Venue, admin, postage and marketing for delivery. A wide range of flexible delivery models will be used.	Based on an example 6 x 3 hour sessions delivered to 10 carers. £1000 per 6 week programme x 400	400,000

Carer Respite – assumes 25% of carers will need respite.	£12 per hour x 4 hours per session = £288 per carer.	288,000
	<b>TOTAL LOCAL COSTS PER ANNUM</b>	<b>1,676,000</b>

<b>NATIONAL COSTS</b>		
National post to promote co-ordination and delivery		40,000
Development and promotion of training materials for local delivery (partnered by academic body to assure quality)		83,000
Independent Evaluation		<b>25,000</b>
	<b>TOTAL NATIONAL COSTS PER ANNUM</b>	<b>148,000</b>

	<b>COMBINED PROGRAMME COSTS PER ANNUM</b>	<b>1,824,000</b>
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## Carer Advocacy

### 2.13 Introduction

*“The Scottish Executive and local and health authorities should consider increasing the capacity of local voluntary sector partners to deliver a range of local support to include:*

- *carer training and peer support;*
- *emotional support and counselling;*
- *breaks from caring; and*
- *carer advocacy”*

*(Rec. 18, The Future of Unpaid Care in Scotland)*

Advocacy services provide crucial support to vulnerable and excluded groups of people in Scotland to ensure their views and needs are heard and acted upon. Many unpaid carers, as a result of the impact and intensity of their caring responsibilities, feel isolated, vulnerable and excluded, and benefit from advocacy support to have their concerns heard and addressed.

Effective carer advocacy benefits both the carer and service user who may rely heavily on the support of unpaid carers to assist them to live independently in the community and to maintain their quality of life. The needs of carers must be recognised to enable them to continue to support the person they care for.

The needs and views of carers may not always be the same as those of the person they care for. For that reason, separate advocacy services are necessary. Most established advocacy services work only with people using services, not with carers. The need for more carer advocacy services was evidenced in Care 21’s national carer survey in 2005 where a high number of carers (18% of 1,720 respondents) chose ‘more advocacy’ as the third most important priority to improve the lives of carers in Scotland. (see table below)

<b>What needs to be changed to improve the lives of carers in Scotland %</b>	
Financial / resources	19
Respite / carer breaks	18

The high importance attached to advocacy can be explained by the fact that 70% of carer respondents to the national survey provide personal and medical care in their caring role, 63% had been caring for 50+ hours a week, and 44% had been caring for over ten years. This suggests a clear correlation between growing need for advocacy support with growing intensity and length of caring.

## 2.14 Policy Context

Listening to the voices of patients, service users and carers, and ensuring those voices are heard, are important aspects of the Scottish Executive's agenda. Independent advocacy is recognised as a crucial element in achieving social justice – a “way to ensure that everyone matters and everyone is heard - including people who are at risk of exclusion and people who have particular difficulties in making their views known” (Independent Advocacy: A Guide to Practitioners, 2000)

Following publication of **Independent Advocacy: A Guide for Commissioners** (September 2000) the Executive's commitment to independent advocacy has been reflected in **Partnership for Care** and **Our National Health** and the reforms embodied in recent policy and legislation, such as the **Adults with Incapacity (Scotland) Act 2000**, **The Same As You** and the **Mental Health (Care and Treatment) (Scotland) Act 2003**.

Provision of Independent Advocacy is also part of the government's wider agenda of Patient Focus and Public Involvement and has three key aims:

- **participation** by service users, carers and local communities. This should mean that their views are actively sought, listened to and acted on; and treated with the same priority as clinical standards and financial performance;
- **empowerment** of individuals and communities, to enable them to increase control over and improve their health; and
- **partnership** between clinicians, professionals, service users and carers in understanding a person's condition and making decisions about the right treatment and care.

## 2.15 Current Provision

Prior to 2007, carer advocacy services emerged in three areas in Scotland, in response to local carer need and demand: the Highlands (Princess Royal Trust Highland Carers Project), Edinburgh & the Lothians (VOCAL) and the Princess Royal Trust Renfrewshire Carers Centre).

All three services are linked to the local carer organisation and are, as such, not independent in statute or premises, but operate within professional and nationally recognised advocacy standards independent of the parent organisation. All three services have also undergone independent service evaluation, Lothian and Renfrewshire services by the Scottish Executive supported Advocacy Safeguard Agency, the Highlands service by a local consultant who was commissioned by Highland funders.

All three services are in early discussions with the Scottish Independent Advocacy Alliance (SIAA) over future accreditation of local carer advocacy services. Existing carer advocacy services operate different models which evidence the scope for diverse local responses to advocacy demands:

- ❑ VOCAL's Lothian Carer Advocacy Service receives £33,000 from NHS Lothian through Lothian's Independent Advocacy Plan, but this is not matched by Lothian's four local authorities. The grant funds a full-time Service Co-ordinator who trains and supports 12 volunteer advocates. Volunteer advocates operate throughout the four Lothian authorities. The service supports over 75 carers every year and deals with increasingly complex issues and situations.
- ❑ Highland Carers Project Advocacy Service currently receives £116,000 funding through the NHS Highland/Highland Council Advocacy Plan. The service employs five carer advocacy staff (three full-time equivalent) who also support ten volunteer advocates. Carer beneficiaries increased year on year from 100+ (04-05), to 140+ (05-06) and 160+ (06-07), with an increase in the number of issues carers sought advocacy support for increasing from 127 (04-05), to 179 (05-06) and 200 (06-07)
- ❑ Renfrewshire Service receives total funding of £62,434, one third statutory partners Renfrewshire Council and Argyll & Clyde NHS (£19,195) the remaining two thirds from the Big Lottery Fund (£43,239). The service employs four staff (2.1 FTE), two sessional workers and several volunteer advocates. 150 carers have benefited from the service over the past 12 months.
- ❑ Inverclyde Carers Centre have recently been awarded approx £10,000 funding from local statutory partners for a part-time 15 hour carer advocacy post and expect to start this service in February 2007.

As statutory and voluntary sector partners increasingly succeed in identifying carers in the most intensive and long-lasting caring situations, demand for advocacy work will continue to increase to address complex and protracted issues of unpaid care.

### **General Aims and Objectives of Carer Advocacy Services**

Carer advocacy services will enable carers to have their voices heard, their rights acknowledged, and their concerns addressed, with the help of a trained advocate.

Objectives:

- ❑ Supporting individuals to speak up for themselves and make their views and wishes known
- ❑ Providing support to individuals who are unwilling or unable to self advocate
- ❑ Enabling people to access the information they require, to understand the options open to them
- ❑ Enabling people to make informed choices
- ❑ Enabling people to make links with service providers, professionals and appropriate support agencies
- ❑ Recruiting, training and supporting volunteer and peer advocates
- ❑ Participating in agreed system of monitoring and evaluation

- ❑ Raising awareness among carers, service users and service providers, of the values, principles and availability of independent advocacy.
- ❑ (Raising awareness among service providers of the role and needs of carers)

### **2.16 Investment Proposal**

This proposal sets out a long-term target of providing dedicated advocacy support to 6,200 carers in Scotland every year. This would represent

- ❑ 3% of carers who care for 50 hours or more a week (3,500 carers)
- ❑ 2% of carers who care for 20-49 hours per week (1,200 carers), and
- ❑ 0.5% of carers who care for less than 20 hours per week (1,500 carers).

Existing experience suggests that well-supported and securely funded carer advocacy services can support 60 carers per annum per professional full-time advocate, and 6-10 carers per part-time volunteer advocate. This takes into consideration that carer advocacy cases are often complex and long-lasting, eg. where the issues are housing problems, adaptations of the home, access to regular respite or mainstream education.

**To support 6,200 carers per annum through 75 advocacy posts (FTE = full time equivalent) and 200 volunteer advocates will require investment of £3 million per annum.** This calculation is based on the average cost per FTE post of £40,000 per professional advocate (full-time equivalent; salary and overheads), with each post on average supporting three volunteer advocates.

## Section Three

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### Conclusion

The Care 21 report *The Future of Unpaid Care in Scotland* evidenced five important messages

- Unpaid carers are the largest group of care providers and as such, the largest component of the Scottish care 'workforce'
- Unpaid care is growing in importance as people live longer and receive more care at home. The capacity and quality of support we give to family carers is therefore crucial
- Scotland's progressive policy direction for unpaid carer is not matched by local practice and service capacity
- Carer support and service standards vary across Scotland. Excellent practice and effective choices exist, but lack sustainability as a result of short-term funding and insufficient capacity
- Existing carer support services reach less than 12% of the carer population. Increasingly systematic carer identification will increase demand on local carer support.

This capacity report sets out current service capacity of local carer organisations with key areas for investment to meet future demand and improve the quality of life of unpaid carers whilst also maximising their contribution.

Submitted to The Scottish Executive by

The Coalition of Carers &  
The Princess Royal Trust for Carers

January 2007

## Appendices

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### Appendix A – Policy Context

*“As the Care 21 report highlights, the importance of informal care will only increase over the coming years.”*

(Lewis Macdonald, MSP, Deputy Minister for Health and Community Care)

Throughout Europe and the UK, policy development on care provision and the role of unpaid family care is increasingly central to national debates on the future of public services – a direct result of demographic change and a future scenario where public services are not expected to match individual demand and expectations.

The Scottish Executive is leading European wide acknowledgement and recognition of the role of unpaid carers. This section sets out briefly the most significant legislation and policy drivers which will shape future support for unpaid family care.

The **Community Care and Health Act 2002** set out in legislation recognition and rights of unpaid carers as key partners and providers in the planning, design and delivery of care.

Subsequent guidance – **Scottish Executive Circular CCD2/2003: Carers – Guidance on Section 8-12** – provides in-depth and comprehensive guidance to local and health authorities on effective interpretation and implementation of the Act.

The **Mental Health (Care and Treatment) (Scotland) Act 2003** sets out that mental health service users and their carers must be properly involved in decision making and have their own support needs addressed.

The Executive’s White Paper **Partnership for Care** (February 2003) set out the agenda for partnership working between health and social care agencies in Scotland.

Building better health and social care services around the strengths and needs of Scottish communities underpins the reforms included in the **NHS Reform (Scotland) Act 2004**. Community Health Partnerships (CHPs) were a central plank of that vision. Their role focuses on local service delivery through which health improvement, and shifts in the balance of care, will be delivered by the NHS, local authorities and the voluntary sector, with greater involvement of service users, carers, staff and independent contractors.

The Care 21 report **The Future of Unpaid Care in Scotland** (September 2005), and the subsequent **Scottish Executive response to the Care 21 report** (April 2006) marked a decisive move away from reactive policy development to preventative planning of future need and provision.

In parallel policy developments, Professor David Kerr’s report **Building a Health Service Fit for the Future - A National Framework for Service Change in the NHS in Scotland** (May 2005) and the Scottish Executive’s full endorsement and response **Delivering for Health** (November 2005) marked a further milestone for carer recognition and the role of the NHS in supporting carers, set out in Chapter 5 of the Kerr report Vol 2 **Self-Care, Carers, Volunteering and the Voluntary Sector: Towards a More Collaborative Approach**.

**Changing Lives** (February 2006) – the Scottish Executive’s 21<sup>st</sup> Century Social Work Review – further cemented recognition of the role of carers in social care

provision and delivery, and embedded the centrality of personalisation in the future direction for public care service provision.

From Scotland's three key long-term strategies for carers, NHS and Social Care further strategic reviews of service provision are already emerging. Of these, new directives for General Practitioners – ***Direct Enhanced Services for Carers*** (April 2006) – and the Review of Nursing in the Community in Scotland – ***Visible, Accessible and Integrated Care*** (November 2006) – are examples of increasing carer recognition and mainstreaming of carer support.

For service users and their family carers, these and many other related policy developments – in Scotland and UK wide – develop the fundamental principles and direction of independent living and care services: enhanced rights and participation of the individual over care planning and service design; greater control over the purchasing and commissioning of services; and a higher standard and quality of service provision.