



# **The Princess Royal Trust for Carers**

**Social Impact Evaluation of five Carers' Centres using  
Social Return on Investment**



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## **The Princess Royal Trust for Carers CEO's Foreword**

Carers frequently tell us how their lives have been transformed by getting the right information and support. We know how important this is, and how it can help not just an individual carer and the person they care for, but also help reduce costs for society.

Knowing this is one thing – demonstrating it, another. The idea of exploring social return on investment came from conversations with Sue Reeve, Chief Executive of Carers in Hertfordshire who was aware of the work of Baker Tilly in this field. We had an opportunity to pursue this thanks to some funding provided by the Department of Health to assist with business development in The Network of Carers' Centres.

My thanks go to the representatives from five of the Carers' Centres across England – Diana Jones (Lewisham), Anna Jackson (Harrogate and Craven), Esther Pacitti (Suffolk), Roma Mills (Hertfordshire) and Kerrie Smith (Westminster). They have provided the evidence required for Baker Tilly's analysis and spent time as a group in analysing it. This means that we know the information is robust and grounded in the everyday work and experience of carers' support staff. Their input into the process has been critical in producing a template for a process which we hope can be replicated by other centres to demonstrate similar result.

We are also grateful for the professional support of Jim Clifford and his team – Chris Theobald and Stephanie Mason, who patiently took us through the process, helped us to understand what was needed and applied their expertise to the information to come up with the results you will see in the report.

I hope this report will help you to understand the challenges carers face and how they can be supported by Carers' Centres. I am sure you will agree that it provides a great argument for funding these services and for the added value achieved by siting all those services together in one place.

Carole Cochrane,

Chief Executive

The Princess Royal Trust for Carers

March 2011

## **The Princess Royal Trust for Carers Introductory Comments from Jim Clifford**

There are around six million people in the UK that care for a friend or family member, selflessly giving of their time and skills to meet the needs of the people they care for. Carers typify what some are now calling the 'Big Society', but in acting as they do, they require support to ensure that they are physically, mentally and financially empowered.

In the course of our work with The Princess Royal Trust for Carers, we have seen many moving examples of how Carers' Centres have provided much needed moral and practical support to carers. It is interesting to note that a typical response from a carer upon discovering their local Carers' Centre is anger that no-one told them about it before. This highlights the immediacy of the difference that a connection to a Carers' Centre makes.

This analysis highlights the value of this work by reference to the difference in outcomes that can be achieved by Carers' Centres in the lives of carers and the people they care for. To do this, we have used five Carers' Centres as a sample of the wider national network. The result of this work is an evaluation of the annual gain to society of the work done by these five Centres, with the intention that others will be able to use the findings of this report as a platform for their own evaluations.

The findings of this report are striking: the five Carers' Centres generate annual gains to society of at least £73 million, set against total annual funding of less than £5 million across all five centres. This leads the reader to enquire further: 'what are Carers' Centres doing that they achieve so much?' Such enquiry highlights the varied activities undertaken by Carers' Centres and their responsiveness to individual needs, but also highlights that this is only a partial evaluation of the wider gains from their activities. These wider gains (New Philanthropy Capital describe several of these as "social wellbeing") are nonetheless of significant value and should not be disregarded for their not being attributed financial measured in this study.

Following the work by new economics foundation over the past decade, and latterly the Scottish Enterprise-sponsored work, the Social Return on Investment methodology has been published in a Cabinet Office paper. Leading commentators and researchers, including nef, New Philanthropy Capital, SROI Network, and ourselves and Cass Business School recognise that, although there are some wrinkles to be ironed out, this is a practical and workable solution to demonstrating social impact. With such a need to focus on this during times of cuts in public funding, and increased social pressures, this is needed now more than ever. It is rightly described by NPC in their 2010 position statement as "an incredibly useful tool."

The methodology used in this research project, and indeed the majority of similar projects we are undertaking, is Action Research, also known as Action Science. This allows the organisation to be supported by the researcher in learning about itself. In this context, it gathers quality information, from those that best understand it, building in relevant, validated third party data, and giving the organisation the knowledge to be able to embed it in its performance monitoring systems: all in one go. It works, and delivers results cost-effectively.

SROI can become a process-driven exercise in which the answer emerges as a function of the process. It can also suffer from the use of financial proxies that have a poor correlation with the outcomes they attempt to measure, or are based on over-enthusiastic assumptions, and a lack of robustness in linking outcomes to the activities in which they originate. This is not the case here. The evaluations have been developed with real thought, care and prudence, and are soundly based on validated underlying data, with conservative assumptions where such are necessary. It fairly represents the very valuable contribution of Carers' Centres to local government and its communities and others, and to the wider UK economy in the fields evaluated.

This is a carefully-constructed, conservative, informed and exciting piece of work that adds to our understanding of social impact. I look forward to it both informing the ongoing development of the SROI methodology, and becoming the foundation for more focussed development of The Princess Royal Trust for Carers' mission.

***Jim Clifford***

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**Jim Clifford** is Head of Charity and Education Advisory Services, and chairs the Public Sector Group at Baker Tilly. He was the lead author of the Social Impact protocol for Sector Skills Councils, published in 2010. He is undertaking research into evaluative protocols for transactional decision making (linking Social Impact with conventional valuation and brand valuation) with Professors Palmer and Bruce at Cass Business School's Centre for Charity Effectiveness, where he is a Visiting Fellow. He has recently been appointed as a director of the Centre for Public Scrutiny.

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# Definitions of Terms

The following definitions apply throughout this document, unless the context requires, otherwise:

Term	Definition
<b>CSP</b>	Chartered Society of Physiotherapy
<b>DCF</b>	Discounted Cash Flow
<b>GCSE</b>	General Certificate of Secondary Education
<b>GP</b>	General Practitioner
<b>GVA</b>	Gross Value Added
<b>LA</b>	Local Authority
<b>NEET</b>	Young People Aged 16 to 25 Not in Education Employment Training
<b>NHS</b>	National Health Service
<b>PCT</b>	Primary Care Trust
<b>RCT</b>	Randomised Control Trial
<b>SROI</b>	Social Return on Investment
<b>The Trust</b>	The Princess Royal Trust for Carers



# 1. Executive Summary and Key Findings

## Background to this report

- 1.1 The Princess Royal Trust for Carers (“The Trust”) is a UK-wide network of 144 independent Carers’ Centres, which offer support including information, training, facilitating access to statutory services and benefits reviews. The Trust supports The Network by providing a national voice for carers, and facilitating The Network to provide carers with the support they need.
- 1.2 The Trust’s stated mission is to meet the diverse needs of carers through excellent local and national services. Its strategic aims are:
- ▶ To ensure that carers are able to influence decisions which affect their lives;
  - ▶ To work effectively with Carers’ Centres and other partners to develop, promote and deliver high quality services for carers;
  - ▶ To raise awareness of carers and the contribution they make to society; and
  - ▶ To secure the sustainability of The Trust and to effectively manage its resources.
- 1.3 The purpose of this report is to evaluate the benefits to key stakeholder groups of the key activities undertaken by five Carers’ Centres, located in:
- ▶ Harrogate;
  - ▶ Hertfordshire;
  - ▶ Lewisham;
  - ▶ Suffolk; and
  - ▶ Westminster.
- 1.4 We have focused on four key areas of Carers’ Centre activity to provide a framework on the basis of which other centres can evaluate and explain their work and its impact:
- ▶ Drawing carers in (i.e. carer identification);
  - ▶ Advice, Information provision and practical support;
  - ▶ Learning and development; and
  - ▶ Carer involvement.
- 1.5 Carers face a number of challenges in relation to their work with the people that they care for as well as their personal wellbeing. In particular, carers are likely to develop or experience a worsening in pre-existing medical conditions. According to a study by the Social Policy Research Unit, carers are likely to experience emotional and mental health problems, as well as diminished immune response and susceptibility to physical illness and injury<sup>A</sup>.
- 1.6 Our approach to this study has been to evaluate the improvement in outcomes for carers achieved by the work of Carers’ Centres, based on a detailed evaluation of five case studies considered by the Carers’ Centres to be typical of their caseloads. These have been evaluated using life course analysis, under which the effects of the Carers’ Centre’s work is shown in a train of events for the beneficiary over a number of years as different life courses ensue. From a blend of different likely outcomes spanning the range of real life consequences that are found typically to arise, a weighted average social impact per carer (i.e. the average net gain to society from the life course analysis, weighted according the proportion of carers that fall into each case study category: for further detail see section 5) has been derived and used to extrapolate the benefits achieved by the five Carers’ Centres in total. This has then been attributed to the areas of work listed above (§1.4).

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<sup>A</sup> Hirst, M., 2004, *Hearts and Minds: the health effects of caring*, Social Policy Research Unit, York

- 1.7 This evaluation does not include a review of the social impact of The Trust itself. Rather, it has commissioned this work on behalf of The Network in order to highlight the valuable contribution of Carers' Centres to key stakeholders.
- 1.8 An SROI Project Team of representatives from each of the Carers' Centres and The Trust was convened, including representatives of each project, using Action Research (see Appendix A) as a methodology for gathering and testing data and assumptions.
- 1.9 This report includes:
- ▶ An overview of social impact and other key methodologies used in this work;
  - ▶ An analysis of the activities and outcomes of the above programmes and centres;
  - ▶ An overview of how those outcomes may be measured using financial proxies;
  - ▶ An overview of the results of the evaluation; and
  - ▶ A detailed presentation of the models and assumptions used in the evaluation.
- 1.10 To the greatest extent possible, Baker Tilly has obtained evidence to support inputs and assumptions used in evaluation models. Where no evidence was available, the project team has used assumptions that they believe to be reasonable as inputs to the model, and Baker Tilly has reviewed and challenged those assumptions during the course of the research.
- 1.11 The Trust and the Carers' Centre representatives have reviewed the content of this report and the models and have agreed that, to the best of their knowledge and belief, the assumptions used for the purposes of this report are accurate and/or reasonable for the purposes of this SROI Project.

## Results of the evaluations

- 1.12 In this exercise, a small number of key assumptions has been identified upon which to base the evaluations. We have worked with project representatives to develop a prudent result at a high level. It has been considered important to present a more defensible, prudent analysis than one which is overly complicated and risks overstatement.
- 1.13 Detailed models and commentary thereon are included as Appendices B and C to this report. The overall findings for the five centres in total for each of the areas of work listed at §1.4 are summarised below:

Summary evaluation	Proportion of gains attributed - consensus across five Centres (%)	Benefits/gains due to each activity (£'000)
Drawing carer in	14%	10,926
Information and planning	38%	27,314
Training and learning development	13%	9,105
Carer involvement (including the value of carer time)	10%	7,427
Other services	13%	9,105
Premium for holistic approach	13%	9,105
<b>Total</b>	<b>100%</b>	<b>72,982</b>

*\*Note total does not equal 100% due to rounding*

- 1.14 The overall evaluated outcomes are shown net of appropriate deductions for deadweight (the change that would have happened anyway), alternative attributions (the proportion attributable to other interventions) and displacement (cost of dis-benefit). The resultant total has been attributed by the participants based on internal review, arguments and debate. The aspects of those operations to which the benefits are attributed are the four areas noted in §1.4 above, 'other' services not specifically noted in this report and the premium achieved by providing these services holistically rather than on a more piecemeal (and arguably less effective) basis.
- 1.15 Hence, these benefits take reasonable account of the key areas of deduction required in SROI evaluations (three standard areas plus risk, which is also needed). These are:
- ▶ Deadweight - gains that would have happened anyway;
  - ▶ Alternative attribution - where part of the gain is more reasonably attributable to a partner or third party; and
  - ▶ Displacement - where the gain is tempered by a lesser dis-benefit.
- 1.16 Based on the SROI Project scope and the specific areas of Carers' Centre activities / services provided, the table above highlights that the areas of work evaluated in this report generate benefits of some £73 million per annum. The approach to deriving an annualised evaluation is discussed in detail in section 5.
- 1.17 Funding for Carers' Centres has been subject to some variation in recent years. The Action Research group has agreed that typical annual funding is likely to be represented best by taking an average over the past five years. These five Carers' Centres had total average funding over the five years to 2009/10 of between c£0.5m and £1.1 million, with combined annual funding across the five centres of less than £5 million.
- 1.18 On this basis, the annual impact of the benefits evaluated exceeds the total annual funding across the five Carers' Centres evaluated by at least £68 million.
- 1.19 In common with most SROI evaluations, it is not practicable or cost-effective to evaluate every aspect of the effects of the Carers' Centres. This relates often to the wider well-being and less proximate benefits from the work of Carers' Centres. Hence the projects shown above may not reflect full evaluations of benefits including:
- ▶ Personal satisfaction of carers and the people they care for;
  - ▶ Improved social inclusion and economic activity of carers and the people they care for;
  - ▶ The brand value of the Carers' Centres; and
  - ▶ The value of skills development among carers.
- 1.20 Where specific evidence exists, the action research team have sought to evaluate these benefits as noted in the report (e.g. personal satisfaction leading to an increase in economic activity). However, many of these outcomes which could be considered as attributable to Carers' Centres were perceived to be either too remote or subject to uncertainties to be evaluated reliably, and as such have not been included.
- 1.21 As this evaluation does not seek to measure the value of the further benefits listed at §1.19, the value of these outcomes would be incremental to the value shown above. Hence the evaluations shown above are lower than the full value of the outcomes potentially generated by the five Carers' Centres.

## Conclusions from the evaluations

- 1.22 In the words of New Philanthropy Capital in their recent positioning statement on SROI, it is an “incredibly useful tool.” This is apparent here as a significant financial value, based on sound and researched third party data, emerges, even with only part of the specifically funded project work being evaluated.
- 1.23 The totals of £73 million per annum of economic and social gain set against around 7% that in total funding. They provide a fascinating insight into the wider social impact of improving outcomes for carers and the people they care for, and draw the reader into wanting to know how it is done: what are Carers’ Centres doing that they achieve so much?
- 1.24 That enquiry not only tells us more about its activities, but also highlights that this is only a partial evaluation of the wider gains from the work of Carers’ Centres. These wider gains (New Philanthropy Capital describe several of these as “social wellbeing”) are nonetheless of significant social value, and should not be disregarded for their not being attributed financial measures in this study.
- 1.25 The methodology around SROI can become a process-driven exercise in which the answer emerges as a function of the process. It can also suffer from the use of financial proxies that have a poor correlation with the outcomes they attempt to measure, or are based on over-enthusiastic assumptions, and a lack of robustness in linking outcomes to the activities in which they originate. This is not the case here. The evaluations have been developed with real thought, care and prudence, and are soundly based on validated underlying data, with conservative assumptions where such are necessary. It fairly represents the very valuable contribution of Carers’ Centres to key stakeholders, and to the wider economy in the areas evaluated.

## 2. Introduction

### Overview of The Princess Royal Trust for Carers

- 2.1 The Princess Royal Trust for Carers ("The Trust") is the largest provider of comprehensive carers support services in the UK. Through its unique network of 144 independently managed Carers' Centres, 89 young carers' services and interactive websites ([www.carers.org](http://www.carers.org) and [www.youngcarers.net](http://www.youngcarers.net)), The Trust currently provides quality information, advice and support services to around 424,000 carers, including 28,500 young carers.
- 2.2 Each Carers' Centre within The Network is an independent charity in its own right, delivering a wide range of local support services to meet the needs of carers in their own communities. Each provides expertise specific to their particular area of the UK. Carers' Centres' core services include:
- ▶ **finding hidden carers** via outreach in GP surgeries, hospital wards and schools (i.e. drawing carers in);
  - ▶ **finding the right information** for every carer, whatever their circumstances;
  - ▶ **making sure carers'** voices are listened to by local decision makers;
  - ▶ **supporting carers emotionally** and practically throughout their caring journey;
  - ▶ **helping to make caring a positive experience** by helping carers to share experiences and by ensuring access to breaks, education, training and employment.
- 2.3 The Princess Royal Trust for Carers and The Network of Carers' Centres work together so that carers' voices are heard by regional and national decision making bodies.
- 2.4 The Trust employs research and data on carers held by The Network to make the case for Carers' Centres and to instigate change. With considerable experience and knowledge of The Network to pilot new more flexible ways of delivering services, The Trust actively demonstrates how these can be used in different parts of the UK.

### About Carers' Centres: outline of the five included in the study

#### Carers in Hertfordshire

- 2.5 Carers in Hertfordshire was formed in 1995 by carers as a countywide charity and became a charitable company limited by guarantee in 2000. The organisation is an associate member of Carers UK and a member of The Princess Royal Trust for Carers' network of Carers' Centres. A Board of Trustees governs Carers in Hertfordshire and the Memorandum and Articles of Association require that 50% of Trustees must be unpaid family carers. The centre currently has 8,635 carers registered, also 682 young carers and 622 former carers of recently deceased people.
- 2.6 Carers in Hertfordshire's aims are:
- ▶ To ensure all carers receive information, advice and support
  - ▶ To enable carers to participate in service planning and decision making
  - ▶ To be a platform for the voice of carers
- 2.7 Carers in Hertfordshire fulfils these aims through a mix of strategic work, development activity and direct service provision to carers, which includes:
- ▶ The one-to-one Carer Planning Service where Carer Support Workers provide individual carers with the opportunity to talk through their caring role and help them to access support, advice and information.

- ▶ The Carers' Development and Learning Service which offers courses, study days and informal learning opportunities, where carers are encouraged to develop new skills and improve their confidence as well as meet new people and make friends.
- ▶ The 'Make a Difference' service, which is run in partnership with NHS Hertfordshire and which allows carers in need of a break or relief from stress, to choose a break which suits them.
- ▶ The specialist Carers' Involvement Projects which support carers to become involved in the planning, development and commissioning of services jointly funded by Hertfordshire County Council and the NHS.
- ▶ The local *Listening to Carers Days* which bring carers together, irrespective of their caring circumstances to identify problems and issues in their own districts and to develop local action plans to address them.
- ▶ The Carer Trainer Unit which facilitates carer involvement in the training of health and social care staff and of other frontline workers who are likely to come into contact with family carers.

2.8 Carers in Hertfordshire works closely and collaboratively with professional staff in a wide range of voluntary and statutory organisations to link the services and to assist them in developing a carer friendly focus.

2.9 Carers in Hertfordshire principal funders are Hertfordshire County Council and Hertfordshire NHS.

## Carers Lewisham

2.10 Carers Lewisham has been supporting carers in Lewisham for the past 22 years. It provides a wide range of services to anyone caring for a relative or friend with a long term mental or physical illness or disability.

2.11 It aims to be a 'one stop shop' for carers by providing a holistic service, including:

- ▶ Advice;
- ▶ Information;
- ▶ Advocacy;
- ▶ Counselling;
- ▶ Respite services and breaks;
- ▶ Training and education;
- ▶ Family support;
- ▶ Mentoring;
- ▶ Outreach to hidden carers; and
- ▶ Carer awareness for other professionals.

2.12 Carers Lewisham also seeks to enable carers' voices to be heard in service provision, development and delivery. It currently has over 5,100 carers registered 450 of whom are children with caring responsibilities. It offers flexible support and has activities and service provision for adults and young carers in the evenings and at weekends. Most of its services are delivered from a lottery funded building in Forest Hill, but it home visits families where needed and runs support groups and other activities at venues around the Borough of Lewisham.

2.13 Carers Lewisham works in partnership with its local authority, the PCT, the Mental Health Trust and some specific partnership projects with Marie Currie, Family Action and the Stephen Lawrence Trust.

## Suffolk Family Carers

2.14 Suffolk Family Carers is a charity at the core of supporting family carers. It has a proven track record of more than twenty years and can be trusted to listen to and understand family carers of all ages.

- 2.15 It is one of the larger Carers' Centres in the UK, and claims to be well respected nationally and locally and has accumulated a wealth of experience and insight; which it uses to maximise choices for family carers to help them to achieve more confidence and control, enabling family carers to make positive life improvements.
- 2.16 Suffolk Family Carers delivers family carer-sensitive information, advice and guidance as well as support and advocacy services and strives to inform and educate other organisations who may have an effect on family carers' lives.
- 2.17 In a recent survey of family carers known to Suffolk Family Carers (December 2010):
- ▶ 64% said their health is worse due to their caring role;
  - ▶ 67.2% said they understand their rights; and
  - ▶ 89.3% of family carers said Suffolk Family Carers have been available for them at time when they most needed emotional and practical support.
- 2.18 Suffolk Family Carers works with integrity and respect for others, in a non-judgmental way. Its team is skilled and creative with a commitment to ensuring that family carers are recognised, supported and valued and that its response to them is sensitive to individual needs. It regularly receives positive feedback that demonstrates that it is making a difference in the lives of family carers.
- 2.19 It works positively with partner organisations, leading on policy and challenging practice and influencing local strategies which impact on family carers.
- 2.20 Suffolk Family Carers states that it aims to "continue to evolve and adapt to the changing political and strategic environment, using our expertise to train and influence those involved in supporting family carers, consistently maintaining our ethos of listening to family carers and developing and influencing services that meets their needs".

## **Carers Network (Westminster)**

- 2.21 Carers Network Westminster is a registered charity. The organisation was founded in 1991 and was first registered as a charity in 1996. The current charity was registered on 29 May 2003 following constitution as a company limited by guarantee (incorporated on 26 March 2003) and is therefore governed by a Memorandum and Articles of Association, which requires that 50% of Trustees must be unpaid carers. Carers Network Westminster became affiliated to The Princess Royal Trust for Carers in 2000.
- 2.22 Carers Network Westminster's vision is of Westminster as a city where the role of carers is recognised, supported and celebrated.
- 2.23 Carers Network Westminster fulfils its Objects through five key aims:
- ▶ To ensure that carers receive the information necessary to make informed choices about their caring role;
  - ▶ To ensure that carers have the support needed to look after their loved one safely and effectively;
  - ▶ Helping carers to sustain their chosen caring role without damage to their wider family or social life;
  - ▶ To help carers have access to learning, leisure and employment opportunities;
  - ▶ To ensure that the health of carers is protected and promoted through advocacy and services.
- 2.24 The centre currently has 2,300 carers registered. In a recent survey, 96% of respondents said that Carers Network Westminster's support had enabled them to continue caring.



- 2.25 Carers Network Westminster's principal funders are Westminster City Council NHS Westminster. The organisation works closely with these bodies and with over 100 voluntary and statutory organisations across Westminster.
- 2.26 Carers Network Westminster's services include:
- ▶ Practical advice, information and signposting including a quarterly newsletter
  - ▶ Support groups, including specialist support; Mental Health, Older People, Learning Disabilities, Bangladeshi Carers and End of Caring Role
  - ▶ Access to support services in a range of languages.
  - ▶ The Carers' Break scheme
  - ▶ The Carers' Emergency Card Scheme
  - ▶ Training and workshops for carers in carer-specific and non-carer-specific subjects
  - ▶ One-to-one emotional support
  - ▶ Day trips and social events
  - ▶ Group holidays
  - ▶ Carers Network Westminster in-house Carers' Assessment and guidance about statutory assessments
  - ▶ Help and advice with applying for benefits and grants
  - ▶ Consultations with carers to improve existing services
  - ▶ Counselling for carers
  - ▶ Campaigning for a better deal for carers

## **GP, Hospital and Pharmacy Link; Carers' Resource (Yorkshire)**

- 2.27 Founded in 1995, the Carers' Resource has developed as a centre of expertise providing:
- ▶ A direct contact point for carers and professionals for information / advice / support / referral / representation / advocacy;
  - ▶ Specialist emotional support for carers;
  - ▶ Awareness raising and training;
  - ▶ Involvement of and consultation with carers;
  - ▶ Information for service providers and planners; and
  - ▶ Research.
- 2.28 In the past few years, it has received national recognition for its work with primary health care teams, in addition to its specialist outreach work in rural areas, its work with employers and its young carer initiative.
- 2.29 The Carers' Resource was the first established Carers' Centre to be invited to join The Princess Royal Trust for Carers' Network. It holds the Queen's Award for Voluntary Service and the Duke of York's Community Initiative Award. It has the Matrix quality standard award (2004, 2007, 2010) for its information, advice and guidance services and Investors in People status (2005, 2007, 2010) and Investors in Volunteering (2007, 2011).
- 2.30 The Director is Deputy Chair of the Standing Commission on Carers. She worked for six years as a consultant for the King's Fund Carers Impact projects and was Non-Executive Director for Harrogate and District Foundation NHS Trust and its predecessor for eight years.
- 2.31 With more than 60 staff and about 100 volunteers, the Carers' Resource has a versatile and highly experienced team which has developed considerable insight into the specialist nature of carer support and into ways in which health and social care can benefit from services such as ours, to the advantage of carers, users and the delivery of community care.
- 2.32 The Carers' Resource operates several teams that provide specialist support for carers and their families including:



- ▶ **Information team:** providing information and signposting the carer to external sources of information and other services to cover specific illnesses and disabilities to arranging short term respite and holidays and transport to long term care;
- ▶ **Carer support team:** providing tailored support including advice on benefits entitlements, a chance to talk to someone and guidance on the range of local statutory services that are available;
- ▶ **Link team:** providing activities, support groups, lunches and outings as well as home-visits to carers or phone calls to offer companionship and support when they need it;
- ▶ **Children and families team:** offering specialist support for families where parents are caring for children with special needs or where children are young carers (see above). This includes the Going Out scheme, which enables parents to go out knowing that an appropriate sitter is caring for their child;
- ▶ **Changing lives team:** supporting carers to re-engage and maintain learning and employment opportunities. This includes support for carers to ensure that they are given their legal rights at work and supporting them with balancing paid employment with their caring role.

## Case studies of Carers' Centre involvement

- 2.33 In order to find evidence to support the improvement in outcomes claimed by the Carers' Centres, we have reviewed a range of case studies, focusing in particular on case studies that match the case study examples used in the life course analysis. These case studies (an anonymised selection of which is included at Appendix E) highlight key aspects of the support provided by Carers' Centres and the value of this support in the eyes of carers themselves. In many cases, the carers in question attribute the improvements that they have observed in their own lives to the work done by the Carers' Centre in question. This case study evidence provides powerful support for the view that Carers' Centres make a significant contribution by helping carers to access services to which they are entitled.

## Objective of this report

- 2.34 Among the aims of The Trust is the objective to 'raise awareness of carers and the contribution they make to society'. This report has been commissioned to highlight the value to key stakeholders and the wider UK economy of the work done by Carers' Centres to provide support to carers.
- 2.35 Whilst this work has been done based on a sample of Carers' Centres, The Trust's aim for the project is to provide a framework that other centres may be able to use as an evaluation tool. We have, therefore, provided guidance on the use of the evaluation models included in this report to assist other centres in this regard.

## Overview of current issues facing carers

- 2.36 Carers Scotland's report 'Sick, tired and caring'<sup>B</sup>, which was published in January 2011 highlights in stark terms the difficulties faced by carers in relation to their own wellbeing, and therefore the wellbeing of the people they care for. Particularly striking figures include:
- ▶ 96% of carers report a negative impact of caring on their health and wellbeing;
  - ▶ 70% of carers reported suffering with back or shoulder pain;
  - ▶ 86% of carers reported suffering with stress, anxiety and depression;
  - ▶ 42% of carers reported that they developed specific health conditions after they began caring, and a quarter of those with pre-existing conditions reported a worsening of their health after they began caring;
  - ▶ 45% of carers experienced difficulties due to low income. The report notes a well-documented link between poverty and poor health outcomes; and
  - ▶ Employment of carers was raised as a key issue, with 40% of carers believing that support to remain in or return to employment would lead to an improvement in their health and wellbeing.

<sup>B</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

- 2.37 The Health and Social Care Information Centre's 2010 report<sup>C</sup> supports many of the findings from the more recent study in Scotland shown above (albeit this study states that it is less likely to pick up carers providing less than 20 hours of care per week):
- ▶ 52% of carers reported that their physical health had been affected by caring. Specific effects included:
    - ▶ Feeling tired (34%);
    - ▶ General feeling of stress (29%);
    - ▶ Disturbed sleep (25%);
    - ▶ Feeling short tempered/irritable (22%);
    - ▶ Depression (19%);
    - ▶ An existing condition was worsened by caring or a new condition was caused (12%); and
    - ▶ Physical strain such as back injury (11%).
  - ▶ 26% felt that their caring responsibility had affected their ability to take up paid employment, 39% had given up employment altogether and a further 32% had reduced their hours. However, only 18% had negotiated flexible working arrangements with their employer, and, worryingly, only 19% were aware that they have a right to request flexible working.
  - ▶ Only 4% of carers had been given a carer's assessment (typical outcomes from an assessment being provision of mobility aids, additional services for the person they care for and information about benefit entitlements);
  - ▶ 42% of carers had not taken a break of two days or more since they started caring
- 2.38 For young carers (i.e. carers aged up to 18 years of age) there are particularly extreme issues that have long term consequences for their mental and physical health as well as their financial position. Wordsworth (2008) presents several key issues that indicate the impact of caring on the educational and long term employment outcomes for young carers<sup>D</sup>:
- ▶ 22% of young carers have been found to suffer significant educational disadvantage (including bullying, attendance problems or inability to complete homework/coursework). Around half of young carers were found to have missed school because of their caring responsibilities, and most report suffering concentration problems due to late night or early morning caring duties;
  - ▶ Over a quarter of young carers leave school with no GCSEs;
  - ▶ Those carers that do progress on to Further Education institutions often find financial hardship as their caring responsibilities may preclude any form of part-time work. In addition to this, they are unlikely to be eligible for Carers' Allowance (which is only paid to carers aged over 18 years); and
  - ▶ Only a quarter of school leavers that had been young carers have been found to have jobs, and those that entered the labour market have been found to be disadvantaged by poor qualifications or poor school attendance record.
- 2.39 Research undertaken by Manchester Metropolitan University and commissioned by The Trust and Crossroads Care<sup>E</sup> has highlighted that for every pound invested in a young carers' service (specifically, targeting interventions on young carers affected by parental substance misuse and parental mental ill-health), the saving to the Exchequer and wider society as a whole is £6.72. The research also found that (taking all of the evidence into consideration):
- ▶ Young carers' projects have an 11% impact on reducing truancy among the young carers they work with
  - ▶ Such projects are estimated to have a 1% impact on reducing the risk of the young carers with whom they work being taken into local authority care; and
  - ▶ Young carers' projects have a 2.5% impact on reducing the risk of the young carers they work with from becoming teenage parents.

<sup>C</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

<sup>D</sup> Wordsworth, S. (2008), 'Young Carers Report', unpub.

<sup>E</sup> Crossroads Caring for Carers and The Princess Royal Trust for Carers (2008), Economic Evaluation of Young Carers' Interventions, accessed at <http://static.carers.org/files/finalfinal3-4040.pdf>

- 2.40 The research by Manchester Metropolitan University also highlighted several key areas of cost saving for the State from the work of young carer projects:
- ▶ Avoiding a young carer being taken into local authority care: £50,574
  - ▶ Improving a young carer's schooling: £47,931
  - ▶ Avoiding a teenage pregnancy: £130,405
  - ▶ Supporting a young carer to undertake appropriate caring: £7,827
- 2.41 Carers' Centres are a vital resource for carers, providing support, information, training and facilitating their engagement with statutory services (including arranging carer's assessments). In addition, Carers' Centres regularly provide advice on managing discussions with local services in order to ensure the best possible outcome is achieved for both the carer and person they care for. As the Carers Scotland report concludes, *"Providing information, at the right time, so that carers can access available financial and practical support, to manage caring better, reduces poverty, disadvantage and ill-health. Similarly, an improvement in the level of quality of support, or flexibility can help to improve carers' health and prevent ill health...Prevention, earlier intervention and anticipatory care will have greater impact in reducing negative effects."*
- 2.42 In the course of our work with The Trust, we have sought to provide a robust evaluation that highlights the gain, in financial terms, to society from providing such support.

## Typical examples of support provided by Carers' Centres

- 2.43 Carers' Centres pride themselves on providing an 'holistic' service that supports all aspects of a carer's needs, treating each as an individual rather than limiting their support to fixed packages. There are, however, certain key services that are commonly used, and which are felt likely to be directly linked to the achievement of the positive outcomes evaluated in this report:
- ▶ **Information and carer planning:** Carers' Centres provide personalised and locally appropriate information to carers and help them use this information to build the support they need to manage their caring role. This is critical to carers in being able to continue to provide the support they do. Many more caring situations would break down without access to the correct information and help in using it to produce practical results.
  - ▶ **Benefits assessments and form-filling:** Carers' Centres provide information, advice and guidance on the benefits available and help carers to access their entitlements. (e.g. Currently only 11% of carers receive Carers' Allowance and many more carers may be entitled to it). Families living with disability are often dependent on benefits, and even small amounts of money can make a very large difference to quality of life.
  - ▶ **Carers' rights:** Carers' Centre staff can help carers to access the services and support they are entitled to from the local authority and health by assisting them with negotiations with social workers, health professionals and others. Carers have a right to a carers' assessment which can lead to provision of support and services for the carer in his/her own right. Carers' support workers also help carers to access support for the person they care for – relieving the burden of care they carry. Many Carers' Centres provide training to help carers feel more confident in asserting their rights. Getting the right services and support makes it more likely carers will continue to care, and improves their health and wellbeing.
  - ▶ **Training:** Many Carers' Centres run training courses for carers to help them to build the skills they need in order to care as effectively and safely as possible. This can include manual handling, first aid, assertiveness, specialist courses around the needs of the cared for person (e.g. Dementia, additional needs children), money advice, administration of medicines and others. Manual handling training can be very important in decreasing the likelihood of injury to the carer and cared for. Caring with Confidence is a tailored course for carers which has helped large numbers of carers feel more confident about their role. Carer-specific training also provides opportunities for carers to meet others facing similar challenges to them. Carers who have attended courses report greater confidence in caring, better well-being, and a reduction in sense of isolation – all of which make it more likely that carers will go on caring.

- ▶ **Health and wellbeing:** Carers risk ill-health as a consequence of their caring role. This may arise from lack of concern for their own health in the light of the needs of the person they care for or may arise from lack of time or inability to leave the cared for person without support. Carers' Centres encourage carers to think about their own health and wellbeing, and help them to access the services they need – for instance a sitting service to enable them to go to the Doctor's. Centres also help carers to take appropriate breaks from caring which can be vital in maintaining mental and physical health.
- ▶ **Personal development and skills training:** Some Carers' Centres provide courses for carers who wish to develop new skills, rebuild confidence and consider return to work. This may include life coaching, skills audits, courses in particular skills (e.g. IT) and facilitating access to qualifications. By providing this support, Carers' Centres increase the likelihood that a carer will be able to return to paid employment more quickly when their caring role comes to an end.
- ▶ **Negotiations with employers:** Only 19% of carers are aware that they have a right to request flexible working from their employer. Carers' Centres provide advice to carers and can also assist with individual negotiations with employers to help carers come to a satisfactory arrangement so that they can continue to work whilst caring. For many carers, financial security and mental/physical wellbeing are strongly influenced by maintaining at least part-time paid employment. This service helps carers remain self-sustaining and can result in improved health and wellbeing and result in carers being able to care for longer.
- ▶ **Group and individual support:** Carers' Centres also provide emotional support to carers – specifically through time spent by staff, through opportunities to meet other carers for mutual support, through events and drop in sessions. The case studies suggest strongly that carers feel supported by all types of Carers' Centre services – and by the fact that the centre is intended for them specifically. The ability to access all services in one place and with familiar staff makes it easier for carers to move between different services.
- ▶ **Carer involvement:** Carers' Centres enable carers to play their part in developing and improving services both at the Centre and with social and health care partners. Many carers, having built up their knowledge and confidence through accessing centre services, are eager to use their experience to give their views at consultation events and to train professionals.

## Scope and purpose of this report

- 2.44 Baker Tilly has been engaged by The Trust to support it in investigating the social impact of activities relating to four key areas of Carers' Centre work. The projects selected for study, which are considered to be representative of the spread and depth of Carers' Centre activities, are:
- ▶ Drawing carers in (i.e. identifying and engaging with the carer);
  - ▶ Advice and Information provision (i.e. provision of expert advice and information on areas such as carers' rights: see examples provided above);
  - ▶ Learning and development (i.e. provision of courses and training to increase the effectiveness of carers and develop their personal skills: see examples provided above); and
  - ▶ Carer involvement (i.e. encouraging carers to become more involved in the strategic planning of statutory services in their community).
- 2.45 This project has been undertaken with an SROI Project team of Carers' Centre representatives, using Action Research (see Appendix A) as a methodology for gathering and testing data and assumptions. Action research has been used as it:
- a. Enables the research to stay close to the data;
  - b. Enables the theory – that is the answer to the research – to emerge from the data as it is gathered;
  - c. Promotes a cyclical revisiting of the data through the research process which promotes internal validity and triangulation of the results: that is the data gathered and the conclusions drawn are better tested;

- d. Through encouraging the organisation itself to learn from the process of the research, its staff are better able to embed the results and benefit from them in developing future strategy: the work can be more useful.

2.46 This report includes:

- ▶ An overview of social impact and other methodologies used in this work;
- ▶ An analysis of the activities and outcomes of the above programmes and centres;
- ▶ An overview of how those outcomes may be measured using financial proxies;
- ▶ An overview of the results of the evaluation; and
- ▶ A detailed presentation of the models and assumptions used in the evaluation.

### **Reliance on work by The Princess Royal Trust for Carers and five Carers' Centres**

2.47 During the course of the work, information and explanations from The Trust and the sample Carers' Centres have been relied upon, including:

- ▶ The nature, outcomes and beneficiaries of their activities; and
- ▶ The assumptions used in evaluating the impact of their services.

2.48 Where possible, assumptions from Carers' Centres have been validated based on independent data or data extracted from Carers' Centre management information systems. Nevertheless, The Trust and the Carers' Centre representatives are responsible for making the assumptions used in this report, and they have confirmed that these assumptions are, to the best of their knowledge and belief, accurate and reasonable.

## 3. Concepts and methodologies used

### Social Return on Investment (“SROI”)

- 3.1 The SROI methodology has been developed in order to help organisations to “[measure and quantify] the benefits they are generating” (per Lawlor, Neizert & Nicholls writing in the SROI guide, 2008). This approach was piloted in the UK through the Measuring What Matters programme during 2002 and has evolved since then as further work has been done to develop the framework around it.
- 3.2 It is increasingly being seen as an “incredibly useful tool”<sup>F</sup> by a number of organisations and key commentators within the Third and Public sectors in the push to measure and evaluate social impact.
- 3.3 There are three ‘bottom line’ aspects of social return:
- ▶ *Economic*: the financial and other effects on the economy, either macro or micro;
  - ▶ *Social*: the effects on individuals’ or communities’ lives that affect their relationships with each other; and
  - ▶ *Environmental*: the effects on the physical environment, both short and long term.
- 3.4 Our primary focus has been on economic and social benefits, rather than environmental benefits, as any environmental benefits generated would appear, for The Trust, to be too far removed from the intended purpose of the original services provided and appear to be too difficult to measure reliably. Where environmental benefits arise from the work of The Trust, the nature of the benefit has been noted, and recorded as an unmeasured additional benefit.
- 3.5 The benefits of using SROI include:
- ▶ *Accountability*: organisations are able to give both the numbers and the story that supports them;
  - ▶ *Planning*: SROI provides a change management tool to assist in the direction of resources towards the most effective services and to assess the viability of potential additional services;
  - ▶ *Cost and time effectiveness*: the measures produce an analysis of the most cost and time effective activities; and
  - ▶ *Simplicity*: impacts can be reduced to a simple comparison of the cost of funding The Trust and the benefits that flow from its core activities to facilitate analysis and give a clear indicator of types and ranges of success.
- 3.6 SROI takes total measurable outcomes, discounted to present value where the benefits occur in the future or are recurring over a period of time, and deducts:
- ▶ *Deadweight*: Outcomes that would have occurred regardless of the intervention;
  - ▶ *Alternative attribution*: Outcomes that arise as a result of intervention by others; and
  - ▶ *Displacement*: Outcomes that are negated or compromised by disadvantages arising elsewhere either in terms of social, economic or environmental damage.

<sup>F</sup> Copps, J. and Heady, L. 2010. *Social Return on Investment: Position Paper, April 2010*. London. NPC. From [www.philanthropycapital.org](http://www.philanthropycapital.org)



- 3.7 A review of academic work and practical examples of SROI in use by the public/private funded sector suggests that the measures fall into three patterns, which have been used in this work:
- a. *Economic benefit created*: where there is an impact on earning capacity or productivity;
  - b. *Costs saved or not wasted*: where the intervention results in a saving, either in the cost of another intervention or in a consequential cost (e.g. introducing prevention to save on the cost of a cure). This may be seen in either removing the need for or increasing the effectiveness of an alternative intervention; and
  - c. *Alternative or cheaper sourcing*: where one intervention directly replaces another more expensive one.
- 3.8 In identifying these benefits, a key underlying requirement is to consider not only the positive contribution that Carers' Centres make, but also the economic damage that is avoided by having it in place. Much of our report involves the quantification of the damage to stakeholders that would result based on these implications. By avoiding this damage, Carers' Centres contribute to the economy just as meaningfully as where the effect is an incremental benefit.

## The case for political support for SROI

- 3.9 Further support for SROI's adoption by the third sector has been seen in the recent report 'Outcome-Based Government', published by the Centre for Social Justice ("CSJ")<sup>G</sup>. This report considers the need to link funding of interventions with the expected outcomes (and their associated value). It suggests that funding should be focused on those interventions that are likely to achieve the highest value outcome: "Improving life outcomes should be the ultimate goal of a government's social policy: if policy makers can better identify failing initiatives, and shift spending toward programmes that effectively deliver sustainable, long-term outcomes, the social and financial returns to society and the public sector will be very great indeed."
- 3.10 CSJ strongly advocates a shift towards evidence-based government, in which funding decisions are based on clear, high quality evidence of impact value, with SROI cited as a "more rigorous approach to performance management while attempting to capture the social and environmental impacts of public spending."
- 3.11 The rationale for adopting SROI may be applied equally strongly to donors, who may rightly expect charities such as Carers' Centres to demonstrate that their support is delivering real value to society.

## Addressing issues concerning the use of SROI

- 3.12 Overall, it is felt that SROI is a vital tool to provide the public/private sector funded bodies such as The Trust with a means to evaluate its wider contribution to Society. However, there are several issues to consider when applying this, that are worthy of mention:
- a. SROI, as it is typically presented, tends to ignore the risks associated with the benefits generated. In the course of our work with The Trust, the Carers' Centre representatives were encouraged to consider the achievable benefit created, and to build in reductions to assumptions to account for risks, where necessary;
  - b. A robust SROI analysis must consider the proximity of the benefit created to the actions of the organisation that is seeking to claim ownership of that benefit. The project representatives were

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<sup>G</sup> Brien, S., 2011, *Outcome-Based Government*, London, Centre for Social Justice

encouraged to focus only on outcomes that are directly attributable to their activities and, where necessary, obtained evidence of the link between the outcome and the Carer's Centre's activities;

- c. SROI is typically presented as a ratio of the value of the benefits achieved per pound spent to achieve those benefits. This may be useful internally to each organisation as a measure of performance relative to prior periods. However, the use of this ratio to compare organisations is inherently flawed due to sector and organisation-specific factors that reduce the level of comparability between organisations. Hence, the results of this report are not presented in the form of a ratio;
- d. There is a danger that organisations seeking to evaluate their impact using SROI may create calculations that are extremely granular to the extent that they become open to accusations of 'spurious accuracy'. In this exercise, a smaller number of key assumptions have been identified and developed with the project representatives to build a prudent result at a high level. It is considered important to present a more defensible, prudent analysis than one which is overly complicated and risks overstatement; and
- e. SROI does not take account of the interrelationship of social impact and brand value. By creating greater social impact, the recognition and perceived quality of an organisation's brand is likely to improve, thus increasing the value of that brand. In turn an entity with a stronger brand may use that to enhance the social impact of its project work. Of note is that The Trust believes that Carers' Centres have strong, well-recognised brands in the areas they serve, which augment their ability to deliver positive outcomes.

## Research methodologies

- 3.13 An SROI Project team from The Trust and the five sample Carers' Centres has worked with Baker Tilly to carry out an Action Research process (see Appendix A). In this, a meeting with the SROI Project team was held to determine the key services that the relevant Carers' Centre services provide, the outcomes of these services and the beneficiaries. Two further meetings were held, in between which the SROI Project team tested out the conclusions from each meeting by practical application in their work, then reporting the results back to the next meeting.
- 3.14 Based on this research, the SROI Project team was consulted on potential means of evaluating the impact of these services by substituting financial measures (proxies) for the outcomes described. Data and assumptions provided by staff at The Trust and the sample Carers' Centres has been relied upon in our analysis; Baker Tilly have acted to facilitate The Trust's understanding of the methodologies used to evaluate the impact but Baker Tilly are not responsible for the assumptions used in the evaluations shown in this report.



## 4. Overview of evaluated activities

### Determining the evaluation approach

- 4.1 During the initial phase of our work, we commenced discussions with the Action Research group to evaluate the four areas of work identified. However, it quickly became apparent that there is a significant level of interdependency between the four areas, and that defining clearly the activities that these areas encompass in a manner that could be applied consistently at any Carers' Centre would prove to be difficult.
- 4.2 In addition, it was noted that the value of providing a 'holistic' service was greater than that of the sum of the constituent parts represented by the four areas of work.
- 4.3 It was, therefore, decided that a different approach would be taken. Rather than seek to evaluate these activities, the group has worked to evaluate the impact of support for carers, taken holistically, on various outcomes for the carer and person they care for based on a series of representative case studies. The case study examples selected were:
- ▶ A young carer;
  - ▶ A carer who is also in paid employment;
  - ▶ A parent carer of a child under the age of 18;
  - ▶ A parent carer for an adult son or daughter; and
  - ▶ A carer of retirement age caring for their spouse or partner.
- 4.4 Real life case studies of carers that fall into these categories which highlight the impact of the support they have received from Carers' Centres are included as Appendix E to this study.
- 4.5 Having identified these scenarios, a common set of outcomes to evaluate was determined with common values defined for an improved/positive outcome. During the Action Research process, each group member was assigned one case study to consider. The participants discussed these case studies with staff at their centre and fed back to the group on the perceived probability that a carer would suffer the outcomes with and without the support of the centre. This feedback was discussed by the group to confirm that the findings from each centre were consistent with the views of the others.
- 4.6 The view on each of these probabilities was then discussed by the participants in light of external research into carer outcomes to ensure that their view on the likelihood of each outcome for a carer was in line with the conclusions of that research.
- 4.7 Further research was carried out into financial proxies that may be used for each of the outcomes used in the life course analyses. This financial proxies derived from this research was shared with the group and adjustments were made to certain of them to ensure that they presented a prudent reflection of the likely costs of each outcome. Given that the work of Carers' Centres may involve increasing the involvement of statutory services, we reviewed research into the cost of that additional involvement from North East Wales Carers' Information Service to derive a typical annual incremental cost of support. These financial measures were agreed by the group and are applied consistently to each case study.
- 4.8 The result is a set of life course analysis models that use a consistent and well-reasoned set of financial measures but for which the likelihood of each outcome is based on the real world probability of that outcome being achieved in each situation.
- 4.9 Based on the number of carers that fall into each of these case study circumstances across the five Carers' Centres, we have evaluated the total gains from each case study.

- 4.10 The carers registered during 2010 that fall into the five case study categories represent 71% of all newly registered carers for the year. On this basis, it is assumed that the five case studies are a relevant sample on which to base an average to extrapolate the gains for the remaining 29%. It is the view of the participants that carers who do not fall into the five categories used are likely to be sufficiently homogenous with those that do for this extrapolation to be meaningful. This has been done using a weighted average economic gain per carer (weighted by number of carers such that those case studies with greater beneficiary numbers have correspondingly greater influence on the average), which has been used to extrapolate the gains across the wider population of carers registered during 2010 at the five centres (i.e. including those that do not fall exactly into one of the above situations). The method of extrapolating the gains to carers registered prior to 2010 is discussed in detail in section 5.
- 4.11 The extrapolated value is then attributed between the following Carers' Centre activities:
- ▶ Drawing carers in;
  - ▶ Advice and information provision;
  - ▶ Learning and development;
  - ▶ Carer involvement;
  - ▶ 'Other' areas of work not specifically mentioned; and
  - ▶ The premium associated with providing holistic (as opposed to piecemeal) support.
- 4.12 For each of the above areas of work, discussions were held with the sample Carers' Centres around:
- a. The nature of the service(s) provided;
  - b. The identification of the direct and indirect beneficiaries;
  - c. The nature of the benefits derived from the service;
  - d. Where relevant, the identification of other agencies or companies that could provide a similar service; and
  - e. The likely cost of providing equivalent services through alternative sources.

## Determining the outcomes achieved by Carers' Centres

- 4.13 A description of typical Carers' Centre activities is shown above (§2.43). In this analysis we have taken the potential improvements in outcomes that may be achieved by providing these, amongst other, services, and have identified the following key areas for financial evaluation:
- ▶ Reduced risk/severity of mental health issues;
  - ▶ Reduced risk/severity of physical health issues;
  - ▶ Reduced risk of severe physical injury;
  - ▶ Lower reduction in working hours;
  - ▶ Increase likelihood of an early return to work when care giving ceases;
  - ▶ Reduced risk of a temporary breakdown in the relationship with the person who is cared for resulting in a temporary residential care placement (for the person who is cared for);
  - ▶ Increased likelihood that a carer will be able to continue caring for longer, thereby delaying a move of the person who is cared for to residential care; and
  - ▶ Improved ability of young carers to engage with education, thereby reducing the risk of being NEET at age 20 to 24.
- 4.14 As empirical evidence to support the connection between the activities of Carers' Centres and the outcomes listed above, we have included a selection of real life (anonymised) case studies at Appendix E.

Many of these case studies have been written by the carers themselves: the powerful conclusions on the importance of the work done by the Carers' Centre in achieving this change is stated in their own words.

## Overview of evaluated outcomes

- 4.15 The table below shows a mapping of the change in life course brought about by the work of Carers' Centres to the proxies used to reflect these changes in this evaluation:

Aspect of life course	Comment	Proxy used
Reduced risk of mental health issues including stress, anxiety and depression	<ul style="list-style-type: none"> <li>▶ Whilst it is inevitable that a carer will be subject to stress, it is possible to put support in place to ensure that this is effectively managed so as to mitigate the impact on the health of the carer.</li> <li>▶ Many of the real life case studies that have been provided to us in the course of this work highlight that the carers themselves have noticed a marked improvement in their mental health following the involvement of their Carers' Centre.</li> <li>▶ According to Carers Scotland<sup>H</sup>, 86% of carers included in a survey reported suffering from anxiety, stress and depression. In the absence of careful management, these conditions might result in a breakdown in the caring relationship or might render the carer unable to deliver care to the standard required by the person they care for.</li> <li>▶ This finding is supported by the NHS carers' survey (2010), which found that 34% of carers feel tired, 29% feel stressed, 25% suffer from disturbed sleep and 19% feel depressed<sup>I</sup>.</li> </ul>	<ul style="list-style-type: none"> <li>▶ The Centre for Mental Health has forecast that the total value of damage arising from mental health issues amounts to some £105.2bn per annum for the UK population aged 18 to 65</li> <li>▶ The Centre for Mental Health has also reported that 23% of the population is likely to suffer mental health problems of any kind</li> <li>▶ On this basis, the average cost per sufferer per annum equates to £11,585 (see Appendix B). We have applied a 40% reduction to this figure to reflect the likelihood that carers may be less likely to suffer some of the more extreme forms of mental illness that would be included in the average</li> <li>▶ Hence, after applying a deduction for prudence, the average assumed value of damage mitigated by effective support is £6,951 per sufferer per annum</li> </ul>

<sup>H</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>I</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

Improved physical health / reduced risk of new conditions or pre-existing conditions being exacerbated by the burden of caring

- ▶ Carers Scotland<sup>J</sup> reports that 42% of carers had developed a physical illness since they started caring, with a quarter of those with a pre-existing condition reporting that it has worsened since they started caring. 67% of carers reported their health to be poor or, at best, average.
- ▶ The same survey found that 57% had one or more illnesses or disabilities and 41% of carers suffer from illnesses including arthritis, high blood pressure, diabetes, chronic fatigue/fibromyalgia and IBS which were caused or exacerbated by their caring role.
- ▶ The NHS carers' survey (2010) found that 52% of carers felt that their health had been affected because of their caring role<sup>K</sup>.
- ▶ In the absence of appropriate support (including effective engagement with health services), a worsening of any of these conditions might result in severe consequences, potentially including hospitalisation of the carer and therefore the need to place the person they care for in temporary care accommodation.
- ▶ We have assumed that a decline in physical health might result in the need for medical intervention in the form of a rehabilitation care episode. The average rehabilitation care episode lasts for two weeks at a cost of £4,254.
- ▶ A Local Authority ("LA") residential care home costs £1,067 per week (for short-term placements), hence a two week rehabilitation episode for a carer would result in a care cost for the person they care for of £2,134.
- ▶ Hence the damage avoided by managing a carer's medical condition is assumed to be £6,388 per annum.

Reduced risk of physical injury

- ▶ Carers are frequently called upon to wash, dress and otherwise lift the person they care for, often placing themselves at risk of physical injury.
- ▶ This is borne out by the findings of the Carers Scotland<sup>L</sup> report that 70% of carers reported suffering from back or shoulder pain.
- ▶ Carers' Centres provide support to carers in obtaining assessments from the LA, and, where appropriate, supports them in making the case for hoists and other lifting equipment to be provided. They also provide training in handling and moving such that carers can reduce the risk of injury by following good practice.
- ▶ The Chartered Society of physiotherapy has estimated that the cost to rehabilitate a patient with lower back pain at £4,526 per episode. This appears to be prudent in light of the cost of surgery of c£7,800.
- ▶ Given that the caring relationship cannot be placed on hold during the rehabilitation phase, it is believed to be likely that the risk of subsequent, and worse, injury occurring increases. We have assumed that a carer suffering physical injury experiences one episode per annum. This is believed to be a prudent assumption in light of the increased risk of subsequent injury following the initial episode.

<sup>J</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>K</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

<sup>L</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

Reduced likelihood of a reduction in working hours (where applicable)

- ▶ For carers that are in paid employment, the risk of a reduction in working hours is significant, in that they may be required to provide care at times when their employer is unable or unwilling to release them. This may result in them giving up work completely or negotiating a reduction to their working hours, resulting in a loss of economic productivity.
- ▶ The NHS carers survey (2010) found that 39% of carers had left paid employment due to their caring responsibilities and that 32% had reduced their working hours<sup>M</sup>. Worryingly, only 19% were aware of their right to request flexible working hours.
- ▶ It is assumed that appropriate support from a Carers' Centre may empower a carer to be able to remain in paid employment. This may include support with negotiations with their employer as well as negotiating for alternative support such as the use of telecare support during the carer's working hours.
- ▶ Using average Gross Value Added ("GVA") per capita for the UK as a whole, and assuming a working year of 46 weeks at 40 hours per week, a per capita GVA of £11 per hour is derived.
- ▶ It is assumed that a carer may have reduced their hours from full to part time to meet their responsibilities as a carer, but that the support detailed (left) enables them to work for an additional ten hours per week.
- ▶ Hence, the assumed value of lost productivity avoided is estimated as £4,994 per carer per annum (i.e. 460 hours x £11).

Increased likelihood of an early return to work after care-giving ceases

- ▶ Carers Scotland<sup>N</sup> found that 40% of carers believe that support to remain in or return to employment would improve their health and wellbeing.
- ▶ Carer feedback suggests that Carers' Centres offer support that increases confidence and deliver training in key skills such as Information Technology that increase the likelihood of an early return to work after care-giving ceases.
- ▶ An unsupported carer may require a lengthy period of rehabilitation as their mental and physical health may have been damaged over a lengthy period such that a return to work is impossible until this damage is resolved.
- ▶ It is assumed that a supported carer is able to return to the workplace 2.5 years earlier than an unsupported carer due to the health and wellbeing factors discussed (left).
- ▶ It is assumed that the carer is identified with four years of care-giving remaining. Carers Scotland's survey identified that the majority of care relationships (66%) last for at least 10 years (i.e. it is assumed that on average the carer is identified after six years). This is consistent with the case study evidence presented by the Action Research Group.
- ▶ A return to full time employment at average per capita GVA per annum has been assumed, giving a present value of incremental productivity (at a discount rate of 3.5%) of £40,990 resulting from an earlier return to work.

<sup>M</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

<sup>N</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

#### Reduced risk of early entry to residential care

- ▶ In the absence of support, it is believed to be likely that a carer's health and wellbeing would deteriorate such that they are unable to continue to provide care.
- ▶ Conversely, a supported carer is believed to be more likely to continue to provide care for a longer period. This support may include 'regular and appropriate' breaks from caring (some 75% of carers felt that this was the most effective support that they could receive)<sup>o</sup>.
- ▶ Other key aspects of support include empowerment to negotiate for increases in provision of statutory services, aids and equipment and technology.
- ▶ We have used a cost per week for LA residential care (for long-term placements) of £986, less a deduction for prudence of 50%.
- ▶ It is assumed that with support, a carer may be able to maintain their role for a further four years, but that in the absence of support they would only be able to provide care for a further year.
- ▶ As above, this implicitly assumes that a carer is not identified until the fifth year of caring (in line with case study feedback gathered by the Action Research group).
- ▶ At a discount rate of 3.5% (see later), this results in avoided costs of LA residential care of £69,394 per carer.

#### Reduced risk of temporary care placement breakdown

- ▶ In the absence of support, feedback from carers suggests that there is a significant risk that the care relationship might break down to the extent that a period of respite care is required before caring can continue (and to avoid a long-term move by the person they care for into residential care).
- ▶ Based on the cost per week of a short-term stay in an LA residential care home of £1,067, less a deduction for prudence of 50% (see above) and an assumed respite period of six weeks (based on feedback from the Action Research group), a cost per episode of £5,321 is derived.

#### Reduced risk of young carer being Not in Education, Employment or Training ("NEET") at age 20 to 24

- ▶ Research by Dearden and Becker<sup>p</sup> indicates that 60% of young carers are likely to be NEET at age 20 to 25. By providing a support network for young carers and encouraging them to engage with their education alongside their caring responsibilities, Carers' Centres reduce the risk that a young carer will become NEET.
- ▶ The Prince's Trust produces an annual report on the cost of youth exclusion that quantifies the economic damage arising from being NEET at age 20 to 24 (i.e. after the period when the majority of education provision has ceased other than adult or vocational education). This damage includes the cost of welfare benefits and lost productivity as well as the evaluated long term impact on wages arising from being out of work during this critical time.
- ▶ The Prince's Trust uses Jobseekers allowance costs of £2,696 per annum and lost productivity of £13,624 per annum to assess the annual damage at age 20 to 24.
- ▶ In addition, research indicates that being out of work at age 20 to 24 results in a lifelong wage penalty compared to a similar individual who was in employment. The present value of this wage penalty is estimated by the Prince's Trust to be £45,000.
- ▶ Based on the above, a total damage value of £104,945 is derived.
- ▶ This is believed to be prudent, given that:
  - ▶ The report uses average wages for employees aged 20 to 24 in place of productivity (on the basis that the group that would otherwise be NEET are likely to have jobs with below average productivity); and
  - ▶ The report implicitly assumes that NEETs enter the workplace at age 24. In reality, many of these people may take far longer to achieve an entry to the workplace.

<sup>o</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>p</sup> Dearden and Becker (2000a), 'Growing up Caring – Vulnerability and Transition to Adulthood', Joseph Rowntree Foundation

- 4.16 The proxies described above have been used for each case study with probabilities assigned to them based on the nature of the individual case study according to feedback from carers and the wider team at each of the sample Carers' Centres. The methodology for deriving an evaluation for each case study is discussed in section 5.

## **Carer involvement**

- 4.17 In addition to the above proxies, we have also considered the value of time spent by carers who are involved at a local level with strategic decision-making bodies that influence the quality of provision for issues such as those described above. These carers are effectively acting as consultants, and as such we have evaluated the time spent on the basis of the alternative cost of sourcing this time at commercial rates for public sector consultants. Further detail on this is provided in Appendix C.
- 4.18 The secondary, and longer term benefit of involving carers at a strategic level in planning of services is that the quality of provision and its relevance to the person who is cared for, and, indeed, the carer, is likely to improve, thereby enhancing the gains achieved in the life course areas noted above. For example, more relevant mental health provision for carers is likely to result in better outcomes than would otherwise have been possible (i.e. a gain is achieved due to the carer's involvement).

## **Summary of outcomes measured**

- 4.19 For the purposes of this evaluation, we have considered eight key outcomes of support for the carer (as shown above) and the alternative commercial value of carer involvement time. The table below shows a map of primary outcomes to secondary outcomes and lists beneficiaries (many of the secondary outcomes arise due to a combination of several primary outcomes):



Primary outcome(s)	Secondary (long term) outcome(s)	Beneficiary
<p>Carer receives better quality information and advice on the practical and financial support that is available to them.</p> <p>Carer accesses counselling and other support services from the Carers' Centre.</p> <p>Carer receives support in applying for additional statutory services such as temporary respite care (e.g. a morning of respite to allow for a shopping trip or visit to the doctor).</p> <p>Carer receives support from the Carers' Centre to negotiate for reduced working hours with their employer.</p> <p>Carer feels less isolated and is more aware that they can talk to the Carers' Centre about their issues and concerns.</p> <p>Young carers are regularly provided with respite time (e.g. days out) and provision is arranged to facilitate better engagement with their education.</p>	<p>Carer (and therefore the person they care for) access appropriate social care, health and welfare benefit services (displacement if capacity did not exist within the services)</p> <p>Carer is more effectively supported and therefore likely to be able to continue caring for longer, thereby reducing the financial burden of care for statutory services.</p> <p>Carer is likely to show better physical health or have a reduced risk of a deterioration of pre-existing conditions.</p> <p>Carer is less likely to suffer from mental health conditions.</p> <p>Carer accesses the physical assistance they need, reducing the risk of injury.</p> <p>Carer (if in paid employment) is better able to remain in control of the person the care for's condition such that they can mitigate any reduction in their working hours, leading to an improvement in their productivity and mental/physical health.</p> <p>Carer is likely to be more able to return to paid employment more quickly after care-giving ceases.</p> <p>Care relationship is less likely to break down temporarily</p> <p>Young carer is less likely to disengage from education and is therefore less likely to be NEET at age 20 to 24 (or longer).</p>	<p>The state bears some of the additional cost of provision if a service is accessed in which there was not existing capacity funded at a fixed cost.</p> <p><b>The state:</b></p> <p>reduced costs of statutory care provision as the carer is able to continue for longer and is less likely to suffer a temporary breakdown leading to statutory care service cover;</p> <p>reduced costs of health and other statutory services for the carer as they are less likely to become ill (mentally or physically);</p> <p>a carer remaining in paid employment is likely to require lower benefits payments, and will pay tax on their income; and</p> <p>young carers are less likely to be NEET and, therefore, less likely to be unproductive and claiming welfare benefits.</p> <p><b>The carer:</b></p> <p>Maintains better physical and mental health;</p> <p>Is more likely to remain in paid employment (where applicable) and therefore less likely to suffer financial hardship;</p> <p><b>The person who is cared for:</b></p> <p>Remains in their own home (or a family home) for longer; and</p> <p>Is likely to receive a higher quality of care.</p>
<p>Carers who become involved in the planning of local statutory service provision give their time as experts, which would otherwise have a commercial cost associated with it</p>	<p>Better planned statutory services are more likely to meet the needs of carer and person who is cared for, thereby enhancing the outcomes achieved from accessing them (see above).</p>	<p>The state – better planned services are more relevant to service users, avoiding waste from over- or under-provision.</p> <p>Outcomes shown above for key beneficiaries are enhanced.</p>

## 5. Summary of evaluation approaches

### Life course analysis

- 5.1 In this evaluation, we have used a life course analysis model, in which:
- ▶ The Action Research group has identified, based on a review of recent research on issues experienced by carers, nine variables that may be affected through intervention;
  - ▶ A financial proxy has been identified for each of these outcomes based on researched data, for example, the cost of residential care is based on the latest available unit cost data per week of Local Authority residential care. The rationale for the proxies used is discussed in detail at Appendix B;
  - ▶ For each of the financial proxies a probability is applied (as a percentage) to reflect the likelihood that an outcome will be achieved (i.e. that a cost will be avoided or that a gain will be achieved) for a typical carer that has engaged with a Carers' Centre. In order to reflect the differing situations in which a carer may be active, we have taken five case study scenarios, each with a different probability weighting against each proxy:
    - ▶ Young carer;
    - ▶ Retired carer for their spouse;
    - ▶ Parent carer of a minor child;
    - ▶ Parent care of an adult son/daughter; and
    - ▶ Carer in paid employment.
  - ▶ The benefits associated with each of these scenarios, based on the probability weightings set against each proxy, are then multiplied by the number of new carers for the last year across the five centres that fall into each category. From this a deduction is made for the typical annual cost of providing the additional support required to achieve these gains. This gives a total net annual gain.
  - ▶ In order to reflect the long term impact of support for these carers, a Discounted Cash Flow ("DCF") model is used to evaluate future gains based on the assumed length of time over which a carer is likely to be active. It is assumed that the carer has already been active for some years prior to engagement with the Carers' Centre. This is based on feedback from each centre that most new referrals have made contact after several years of struggling on their own. The life course model assumes that the carer will care for ten years in total and makes contact in year five (i.e. these benefits occur for five years from the point at which they make contact).
  - ▶ This then gives the total present value of the benefits achieved by the work of a Carers' Centre over the life of the carer. Given that only a five year timescale has been considered, this is felt to be a prudent reflection of those benefits.
  - ▶ The five case study models are then combined to give a weighted average lifetime net gain per carer, which can be used to evaluate all carers (i.e. including those that do not fit with the case study scenarios outlined above). This weighted average may be applied, subject to a review of any local variation in outcome trends, by other Carers' Centres.

### Summary of evaluation models used in this report

- 5.2 Section 4 provides an overview of the outcomes of the support provided by Carers' Centres and the proxies used to evaluate each of these. In conjunction with the project representatives, we have prepared a series of case study models that assess the probability of each outcome occurring given the nature of the individual case study.
- 5.3 In order to assess probabilities for each outcome, we have sought feedback from the wider team at each of the sample Carers' Centres and The Trust, and have obtained anonymised carer case studies that highlight the perceived likelihood of such improved outcomes being realised.
- 5.4 For illustrative purposes, we show below an example of the model used for case study life course analysis, together with guidance notes on its use to show how it may be applied by a Carers' Centre:

Case study illustration - retired carer of spouse/partner	Assumption	Number of stakeholders affected	Evaluated benefits/gains per capita (£)	Evaluated benefits/gains (£)
Number of carers supported	787			
Proportion that would otherwise have mental health issues	80%	629	6,951	4,373,731
Proportion that would otherwise have physical health issues	40%	315	5,321	1,674,068
Proportion that would otherwise suffer physical injury	60%	472	4,526	2,135,924
Proportion that would otherwise reduce their working hours	0%	-	4,994	-
Proportion that would otherwise have a temporary breakdown during the year	50%	393	3,201	1,258,855
Less: additional cost of engagement with services (displacement) if applicable				(786,538)
<b>Total evaluated benefits per annum</b>				<b>8,656,040</b>
Average length of care-giving (years)	5.0			
Discount rate	3.5%			
Annuity factor		4.52		
<b>Value of support to carers during care-giving period</b>				<b>39,082,472</b>
Proportion that would return early to full-time work	0%	-	40,990	-
Proportion of young carers that would otherwise be NEET at age 20 to 24	0%	-	104,945	-
<b>Total value (carer's perspective)</b>				<b>39,082,472</b>
Proportion of cared-for people that would otherwise enter residential care earlier	20%	157	69,394	10,916,205
<b>Total value (carer and cared-for person perspective)</b>				<b>49,998,677</b>
Deduction for those that continue to suffer outcomes	50%			(24,999,339)
<b>Total value (carer and cared-for perspective)</b>				<b>24,999,339</b>

## 5.5 Key assumptions:

- ▶ **Number of carers registered during the current year:** this should be determined from Management Information at the Carers' Centre in question. For the purposes of this evaluation we have been provided with carer numbers as follows:

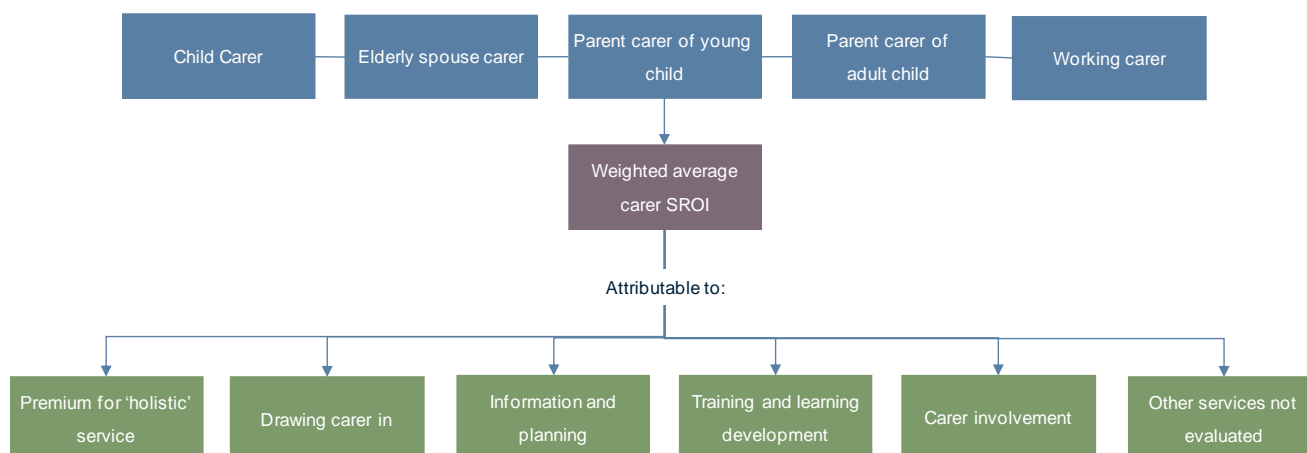
Number of carers registered during 2010	Young carer	Carer in paid employment	Parent carer of minor child	Parent carer of adult son/daughter	Retired spouse carer	Other newly registered carers	Total newly registered	Carers registered pre-2010	Of whom actively engaged
Yorkshire	80	-	161	114	393	724	1,472	2,507	2,507
Hertfordshire	146	197	166	166	-	476	1,151	7,484	7,484
Lewisham	93	86	332	-	127	-	638	2,050	2,050
Westminster	61	79	103	38	85	145	510	1,540	1,540
Suffolk	190	370	195	37	182	-	974	11,964	8,961
<b>Total</b>	<b>570</b>	<b>732</b>	<b>957</b>	<b>355</b>	<b>787</b>	<b>1,345</b>	<b>4,745</b>	<b>25,545</b>	<b>22,542</b>

- ▶ **Evaluated benefits/gains per capita:** these are as discussed above in section 4, and are based on national average data (and therefore should be broadly applicable to any Carers' Centre unless there is clear evidence of local deviation from the average).
- ▶ **Evaluated additional cost of engagement:** a study carried out in Wales by North East Wales Carers Information Service in 2009 highlighted that a typical carer support package cost of c£500 per six month period was observed. Hence, an annual displacement cost of £1,000 per carer is deducted. This is felt to be prudent, as not all carers will require a support package at incremental cost to statutory services (i.e. some services are funded at a fixed cost and have existing capacity to take on additional work with no incremental cash cost).

- ▶ **Assumed proportion of carers that would experience specific outcomes/damage in the absence of intervention:** This is based on judgmental assumptions that are the result of discussion among the Action Research group. In many cases published research is indicative of the likely proportion of the carer population that experience such issues, but taking into account local feedback and the individual case study evidence presented to the group from each centre. Some of these probabilities are age-specific (e.g. a model that considers retired carers should not factor in productivity gains from a return to work or damage arising from being NEET aged 20 to 24).
- ▶ **Average length of care giving:** The external research that we have accessed during the course of our work with the five centres highlights that the majority of carers have been caring for up to ten years. A significant minority continue to care for longer, however it was felt to be prudent to use ten years as the assumed maximum in order to remain consistent with the research data. From discussions with the five Carers' Centres included in this report, we understand that many referrals do not occur as soon as a carer begins their role, but rather that there is a period in which the carer will seek to continue unsupported. Informal feedback suggests that this period may be up to five years, although Carers' Centres are working to reduce the time between caring commencing and identification by the Carers' Centre. For the purposes of this evaluation, it is assumed that a carer has been caring for five years prior to registration with the Carers' Centre, and continues caring with their support for a further five years (i.e. ten years in total). This is felt to be prudent, in that it does not recognise an excessive period over which to evaluate the benefits/gains achieved. Evidence of local deviations from the average may result in a change to this assumption if it is to be applied locally by other Carers' Centres.
- ▶ **Discount factor:** This assumption is used in a Discounted Cash Flow ("DCF") model (see Appendix D) to restate the value of future benefits/gains to its present value after adjusting for the changing value of money over time. This rate is consistent with the rate used by the UK Government for project appraisal, and is consistent with the long term average inflation rate (calculated over 20 years) per the Bank of England.
- ▶ **Deductions:**
  - ▶ The model shown above includes an adjustment for displacement (i.e. the incremental cost of support resulting from engagement with the carer in question), but does not include deductions for deadweight, alternative attribution. These are factored in later when combining the case study models together. Our approach to combining the models is discussed below.
  - ▶ A deduction of 50% is made to the total to reflect the probability that despite the work of the Carers' Centre, some of the outcomes that have been modelled as being avoided may occur in any case (albeit these situations may be more effectively managed with support from the Carers' Centre). The model above is based on externally sourced research on the incidence of negative outcomes among carers, and it reflects the benefits that would be achieved in the event that the entire population of carers served by the five centres was entirely lifted out of such conditions (e.g. if all 80% were to avoid mental health issues). Clearly, this is highly unlikely to be the case, although it is to be expected that most carers will benefit from at least one of the above outcomes. The deduction of 50% is not, therefore, to be read as an assumption that 50% of carers derive no benefit from the service they receive. Rather, it is intended to reflect that some carers may derive more limited benefits due to the nature of the condition of the person who is cared for or their own circumstances over which the Carers' Centre has little or no control.

5.6 The diagram below summarises the approach to combining the various case studies into a single evaluation:

## PRTC - Structure of evaluation models



- 5.7 We have brought the total evaluations from each of the case study models into a single model and applied deductions for deadweight (the value of gains that would be expected to have occurred in any case) and alternative attribution (the value of gains attributable to other parties). For the purposes of this evaluation total deductions of 85% have been used, which is felt to be reasonable and, indeed, prudent.
- 5.8 From the total residual gain due to Carers' Centres, a weighted average gain per carer has been calculated (weighted based on the number of carers brought into each model). This weighted average is then multiplied by the total number of carers across all five centres (i.e. the weighted average from the representative case studies is applied to the wider population. The population that falls into the case study examples used amounts to 71% of the total carer population across the five centres, hence it is felt to be reasonable to assume that the remaining 21% would broadly fall into the same range of benefits/gains generated as those reviewed in the case studies.

## Time-apportioning the life course benefits to match the timing and value of work done

- 5.9 The evaluated benefits for newly registered carers (based on the weighted average) is then apportioned to reflect the timing and attributed value of work done to each of the five years. For this purpose it is assumed that 60% of the gains are made in the first year of contact, with 10% per annum arising in each of the remaining four years. In the event that a carer continues to care for longer than five years additional annual gains are to be recognised at the rate of 10% of the five year gain until caring ceases. The rationale for this split is that whilst it is felt that the majority of the value achieved is attributable to work done in the first year post-registration (i.e. more than 50% of the gain is attributable to that year), it would be understating the importance of ongoing engagement with the carer if 70% or more were to be recognised in that year. On this basis, it was felt that 60% represented a balanced view of the value achieved in the first year post-registration (i.e. mid-way between 50% and 70%). The remaining 40% is then split evenly across the remaining four years, which was felt to be consistent with the relative level of work done by the Carers' Centre in any year after the first year of engagement.
- 5.10 The rationale for recognising the majority of the lifetime benefits achieved by the Carers' Centres in the year in which a carer is initially engaged with is as follows:
- ▶ Whilst there is ongoing work after the first year of contact, much of the evaluated benefit for future years flows from the initial work of identifying the carer and the initial work with them to ensure that they are accessing the appropriate levels of practical and financial support to which they are entitled;
  - ▶ Ongoing support tends to be primarily in terms of ensuring that this support is kept up-to-date with the carer's changing needs and acting as a source of encouragement and moral support rather than

continuing to bring about the significant changes that would be expected in the first year of engagement;

- ▶ Therefore, the majority of benefits achieved in the life of the carer flow from the initial work done during the first year of engagement with the Carers' Centre and as such should be matched to the that year. Logically, even the future gains would not be possible without this initial work, but part of the value of future gains is to be matched against the work done in those years.

## Applying this methodology to pre-existing carers

5.11 In order to account for the benefits achieved for pre-existing carers in the current year, we have:

- ▶ Applied the weighted average lifetime gain to these carers in total;
- ▶ This value is then adjusted to deduct the value of benefits already achieved or that should be recognised in future years (i.e. the life course benefit is adjusted such that 10% is brought into years after the first year of contact – see above);
- ▶ The value assigned to the current year for pre-existing carers from this calculation is then added to the evaluation for new carers registered during the past 12 months.

## Applying the methodology in future years

5.12 In future years, the evaluated gains for newly registered carers should be calculated and then 60% of this gain allocated to the first year of contact, as described above.

5.13 The benefits achieved as regards carers registered in the prior year and before are to be evaluated based on 10% of the life course gain (as shown above). This ensures that future gains are recognised in the period when the work was done to achieve them. It also reduces the risk that gains in relation to carers who continue to receive support for either more or less than five years might be under- or overstated.

## Deriving an annual evaluation

5.14 By applying the above approach, an evaluation of the benefits achieved in each year is derived without double counting, but recognising the value achieved in the lives of carers that have been active for longer than expected in the original life course analysis (or discounting part of the value for those that do not care for as long as expected).

5.15 The detailed workings used for this evaluation are shown at Appendix C.

## Attributing values to key areas of work

5.16 The total value of benefits/gains attributable to the five centres is then calculated, and attributed to each of the areas of work noted above (§4.11) based on group discussion on the relative influence of each area of the achievement of those gains. This stage of the calculation does not impact upon the value of the work of the Carers' Centres included in this evaluation from an external perspective. Whilst the Action Research group has sought to determine assumptions for the attribution to each area of work based on data, much of the discussion is based on the judgment of the group. From an external perspective any inaccuracy would result in a shift of value to other areas rather than a reduction in the value attributable to the Carers' Centre, hence this would not materially alter the conclusion from the review.

## Avoidance of double-counting

5.17 We have distinguished the carers that fall into each of the categories selected for case study analysis from those that do not in order to avoid double counting.

5.18 The approach to future evaluations outlined above (§5.9-5.14) avoids double counting benefits from one year in another.



## 6. Conclusion

### Results of this evaluation

- 6.1 Based on the results of our discussions with The Princess Royal Trust for Carers and the five sample Carers' Centres, as summarised above, and on the results of the evaluation models (Appendix B), the aggregated gains/benefits derived for the five Carers' Centres may be summarised:

Summary evaluation	Proportion of gains attributed - consensus across five Centres (%)	Benefits/gains due to each activity (£'000)
Drawing carer in	14%	10,926
Information and planning	38%	27,314
Training and learning development	13%	9,105
Carer involvement (including the value of carer time)	10%	7,427
Other services	13%	9,105
Premium for holistic approach	13%	9,105
<b>Total</b>	<b>100%</b>	<b>72,982</b>

*\*Note total does not equal 100% due to rounding*

- 6.2 The table above shows total aggregated benefits from the five Carers' Centres included in this evaluation to be c£73 million per annum.
- 6.3 It has become clear from our work with the Carers' Centres that different geographical areas require different approaches. This is shown from the range of views on the relative weighting of the above areas of work as regards their relative importance in achieving the gains discussed in this report. This has no impact on the total gains evaluated, it merely reflects the different ways of achieving these gains. In order to reflect a consensus view across the five centres, we have used an average based on the range of attribution percentages provided by the five centres. The Action Research group has agreed that this represents a reasonable consensus view of the typical work of a Carers' Centre.
- 6.4 Funding for Carers' Centres has been subject to some variation in recent years. The Action Research group has agreed that typical annual funding is likely to be represented best by taking an average over the past five years. These five Carers' Centres had total average funding over the five years to 2009/10 of between c£0.5m and £1.1 million, with combined annual funding of less than £5 million.
- 6.5 On this basis, the impact of the benefits evaluated exceeds the total annual funding across the five Carers' Centres by at least £68 million.
- 6.6 It should be noted that this report only includes the benefits evaluated from selected life course outcomes due to the Carers' Centres activities over a limited period, and therefore if all other life course outcomes from Carers' Centres work were evaluated the total impact would be likely to increase.

### Sensitivity analysis

- 6.7 Various assumptions have been made in the course of preparing this analysis and the detailed tables of calculations in Appendices B and C. Some relate to estimates made by the Action Research group in coming to the views of outcomes, and some relate to the interpretation of information arising from other research work and statistical analyses referenced in this work.

- 6.8 In order to assess the extent to which these assumptions are material, potentially key assumptions have been identified. Each has been subjected to variation within what appears to be a reasonable range, and the effect on the total evaluated outcomes under the study has been recast.
- 6.9 The results of our sensitivity analysis are shown in detail as Appendix F to this report. The conclusion from adjusting certain key assumptions was that the evaluated outcomes continue to outweigh the costs to achieve them even under a combination of the two harshest scenarios.

## Other outcomes not evaluated

- 6.10 During the course of our meetings with the Action Research group, it has become clear that certain key outcomes of its work could not be reliably evaluated in financial terms. The key areas of benefit not included are as follows:
- ▶ General wellbeing of the person who is cared for (other than in terms of reduced likelihood of residential care admission);
  - ▶ The impact of improved carer support on the carer/person they care for's wider family.
- 6.11 Where specific evidence exists, it has been sought to evaluate these benefits as noted in the report. However, it is difficult to evaluate reliably in financial terms the value of increased well-being of beneficiaries. We also note that to quantify the impact on the wider family may be regarded as too far removed from the work of a Carers' Centre, and with too many other variables at work in achieving benefits/gains to be quantified reliably.
- 6.12 As this evaluation does not seek to measure the value of the further benefits listed at §6.10, the value of these outcomes would be incremental to the value shown above. Hence the evaluations shown above are lower than the full value of the outcomes potentially generated by the Carers' Centres.



# Appendices

# A. Notes on Action Research

Action Research, or Action Science as some, including Gummerson<sup>Q</sup> prefer to call it, is a recognised and respected research approach originating in the social sciences arena, which involves the researcher and the researched jointly learning in and investigating the research area. Whilst primarily a qualitative methodology, it can be constructed in such a way as to gather and test data with levels of validity that would constitute scientific research (as opposed to casual enquiry) whilst retaining the proximity to that data that best comes from working with those who are involved with it.

The researcher works with the researched jointly to investigate an issue of common interest. Together they gather data, test and validate it, and draw interpretations and conclusions from it.

Action research is hence an iterative research methodology that is intended to bridge the gap between theoretical research and the practical realities of the real world. As Gustavsen puts it:

*“The point is to understand the world as it is by confronting it directly; by trying to grasp the phenomena as they really are.”<sup>R</sup>*

Reason and Bradbury (2001) define Action Research as *“a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes, grounded in a participatory worldview... It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.”* (2001, p.1).

In simplistic terms, Action Research is collectively learning from experience by sharing that experience with others and taking action to bring about change by building on that experience.

In our work with The Trust, it has been vital that an understanding was gained, not just of how the activities of Carers' Centres could *theoretically* be benefiting the local area, but of how it creates benefit in practice. Theoretical research on SROI methodologies gives us a view on where the benefits may lie, but only through an iterative process of discussing, developing and refining our understanding can a true picture be obtained of where the benefits of the Carers' Centres' activities actually lie.

The process of conducting Action Research may be summarised using the diagram shown below:

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<sup>Q</sup> Gummerson, E. 2000, *Qualitative Methods in Management Research*. 2<sup>nd</sup> Ed. Thousand Oaks, Ca. Sage Publications

<sup>R</sup> 'New Forms of Knowledge Production and the Role of Action Research', Bjorn Gustavsen, *Action Research* 2003; volume 1 at p.153



The diagram shows an iterative five stage approach to Action Research. The way in which our approach fits with this model is described as follows:

1. **Observation:** from our initial discussions with The Trust, it is clear that a lack of understanding of the Social Impact of Carers' Centres may weaken their position when negotiating with funders, thus damaging their ability to continue their work. However, it is also clear that by improving awareness of the extent of its impact on key stakeholders a stronger position might be reached.
2. **Reflection:** by using Social Impact measurement tools such as SROI, it is believed that it is possible to begin to increase the understanding of the benefits Carers' Centres generate among key stakeholders;
3. **Data gathering:** the services that Carers' Centres provide were discussed with a team of project representatives, and the outcomes these projects and services produce and identified the key beneficiaries. A range of possible methods of evaluating these services were discussed using the three models described at §3.7 of this report to cover the concept of value from the perspective of all key stakeholders;
4. **Test claims and conclude:** many of the assumptions used in the evaluation models (Appendix B) are based on data gathered by the five Carers' Centre's management information systems. Copies of the supporting records for such data were obtained. Where, an assumption was required, the Action Research group were encouraged to be prudent in order to avoid overstating benefits. In some cases, assumptions have been informed by data from external sources combined with the use of judgement. Copies or records of any research were obtained;
5. **Monitor improvements:** it is hoped that this work will result in improved awareness of Carers' Centre activities among stakeholders (including funders), and therefore address the risks identified at stage 1 of the process.

Having reached a stage where an improvement is expected, the iterative nature of Action Research allows for further studies to be carried out in future to build on the work presented in this report, including ongoing measurement of benefits and the use of similar methodologies to assess proposed future projects.

Clearly, wherever data already exist to quantify a benefit, they are to be used. However, the absence of observed data, Action Research allows us to gain an accurate perspective on the real benefits that are generated. In some

cases it will be impossible to observe the impact, as to do so would require a comparison between a world in which a Carers' Centre exists and one in which it does not, all other factors being equal. Clearly such comparison will never be possible, and so reliance must be placed on the common-sense and judgment of the Carers' Centre representatives, based on their real-world experience.

Where data may be, but is not currently, observed, our work allows us to refine the list of useful data that may be gathered in future as a basis for refining the measurement of the economic benefit that is generated. This project may therefore act as a platform for identifying further Action Research projects that will develop detailed measurement tools.

Any outline of a research methodology would be incomplete without looking at broader criticisms of it in management science circles. Criticisms of action research are several, but most emanate from proponents of statistical sampling and questionnaire-based research methodologies. In brief, these tend to surround the following areas, each of which is shown with a brief response related both to theory and to this research in particular.

### **How can you assert validity when all the data is of internal origin?**

Bypassing the theoretical debates about the validity of different data sources and the extent to which all are, to some degree, partly objective and partly partisan, the key point here is that the data is not all of internal origin.

Many of the measurement criteria within the financial proxies are:

- ▶ from publicly available data sources, often validated Government data;
- ▶ from appropriately structured pilot studies;
- ▶ from research appropriately undertaken by the subjects' own research team; or
- ▶ separately sense-checked or reviewed by the research team.

### **It is not true research because the researcher influences, and is involved in the outcome....?**

It is true that the researcher is involved in the sense that "the action researcher... may help clients make more sense of their practical knowledge and experience..."<sup>S</sup>.

This is consistent with the second of the seven principles of SROI: Measurement with people.


If the researcher facilitates the better collection and interpretation of data from the researched and leaves them with an understanding and knowledge to enable them to embed that in future action, then this active involvement must be seen as a virtue and not a weakness. It improves the understanding of data gathered and at the same time, seeks to embed the results in the organisations (the final stage of the SROI process).

Berg<sup>T</sup> summarises the strengths of action research in these fields as follows:

- ▶ "a highly rigorous, yet reflective or interpretative, approach to empirical research;
- ▶ the active engagement of individuals...in the research enterprise;
- ▶ the integration of some practical outcomes related to the actual lives of participants in this research project;
- ▶ a spiralling of steps..."

<sup>S</sup> Gill, J. And Johnson, P. 2002. Research Methods for Managers. 3<sup>rd</sup> Ed. London, Sage. p.92.

<sup>T</sup> Berg, B. 2009. Qualitative Research Methods for the Social Sciences. 7<sup>th</sup> Ed. Upper Saddle River, NJ. Pearson. .248.



It has been found, in this study and other similar ones, that Action Research provides an ideal foundation approach for developing a Social Impact Evaluation and embedding it in an organisation.

## B. Detailed analysis of financial proxies used

### Background

In the life course analyses used in this evaluation we have used a common set of proxies to measure the impact of the work done by Carers' Centres on key outcomes, based on the specific nature of each of the case study examples. The workings of, and assumptions to, the case study evaluation models are discussed later (Appendix C). In order to avoid repetition later, we discuss the sources and workings behind each of the proxies used below.

Clearly, not all of these proxies will apply in all cases and so the evaluation models shown in Appendix C assign a probability to each of them. Where a proxy is deemed to be recurring in future years, it is implicitly assumed that a carer who has experienced this problem in, say, year one may be replaced by another in the event that there is a change in circumstances for year two, and so on (see later). It is, however, felt to be likely that a carer that has a high probability of facing the issues set out below will continue to do so for the duration of their care giving.

These proxies do not take account of deductions for deadweight and alternative attribution, which are included within the case study models. A proxy value for displacement is shown later in this Appendix.

### Detailed analysis of proxies

#### Reduced risk of carer mental health issues

Several research reports have identified the high incidence of mental health problems among carers. Carers Scotland's research highlights that 86% of carers report suffering from stress, anxiety or depression<sup>U</sup>. The Social Policy Research Unit at the University of York indicates that carers report a greater incidence of psychological distress including anxiety, depression and loss of confidence and self esteem<sup>V</sup>.

The NHS Health and Social Care Information Centre report in 2010<sup>W</sup> shows that 29% of carers claimed to be experiencing stress, 25% were suffering disturbed sleep and 19% were feeling depressed (all of which suggest some level of mental health issue). This highlights the heightened risk of mental health among carers, although the risk of conditions escalating can be managed with appropriate support.

Dolan, Fujiwara and Peasgood (2010)<sup>X</sup> found that 37% of intensive carers (i.e. those delivering at least 20 hours of care per week) had mental health scores that were consistent with depression or anxiety.

Carers' Centres help to provide the support and advice that carers need to manage their mental wellbeing, and are able to facilitate a carer's engagement with other services in this regard. In the absence of this support, it is likely that stress and anxiety might lead to a vicious circle that culminates in the breakdown of the caring relationship and long-term mental health damage to the carer.

The table below shows the assumptions and calculation of the value of damage to society avoided by supporting and improving the mental health of a carer:

<sup>U</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>V</sup> Hirst, M., 2004, 'Hearts and Minds: the health effects of caring', Carers UK, London

<sup>W</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

<sup>X</sup> Dolan, P., Fujiwara, D. & Peasgood, T. (2010), 'The impact of the carer burden', unpub.

Mental health - carer	Assumption	Calculation	Evaluated benefits/gains (£)
Value of economic damage per annum due to Mental health issues*	105,200,000,000		
UK population aged 18 to 65	39,481,800		
Proportion of population suffering mental health problems of any kind	23%		
<b>Average damage per person per annum</b>			<b>11,585</b>
Reduction to apply to national average	40%		(4,634)
<b>Therefore damage value used in this evaluation</b>			<b>6,951</b>

\*Evaluation relating to adults aged 18 to 65

The Centre for Mental Health forecast in 2004 that the damage arising from mental illness was worth £105.2 billion per annum. Its research suggests that 23% of the population aged 18 to 65 is likely to suffer from some form of mental illness. Based on a UK population aged 18 to 65 of 39.5 million people (i.e. the part of the population that matches the findings of Centre for Mental Health's research), this indicates an average value per sufferer of £11,585 per annum.

From our discussion with the Action Research group, some concern around the use of this average arose. Whilst its use as a proxy may be justified given that it represents an average, we note that mental health includes a wide range of conditions, of which those noted above are not the most severe. Accordingly, a judgmental deduction of 40% has been made to this assumption to account for the likelihood that the damage associated with the conditions typically cited by carers may be below average. This is felt to be a reasonable reflection of the potential damage arising from failing to manage mental wellbeing among carers.

## Reduction in risk of physical illness among carers

The SPRU's work highlights that carers are likely to experience "diminished immune response, and susceptibility to physical illness and infection such as flu<sup>Y</sup>. It also notes that "poor health in carers can often lead to older people's greater use of health services, including admission to, delayed discharge from, or unplanned readmission to hospital; referral to a day hospital or geriatric unit; and admission to residential care or nursing homes".

Carers Scotland quantifies the proportion of carers likely to suffer from physical ill-effects due to their caring role<sup>Z</sup>:

- ▶ 96% of carers reported a negative impact on their health and wellbeing due to caring;
- ▶ 41% of carers suffer from illnesses including arthritis, high blood pressure, diabetes, chronic fatigue/fibromyalgia and IBS; and
- ▶ 42% of carers reported that they had developed medical conditions after caring commenced, and a quarter of those with pre-existing conditions reported a worsening after caring commenced.

The NHS' 2010 carers' survey<sup>AA</sup> highlights that 52% of carers felt that their health had been affected because of caring, including 6% who claimed that an existing condition had developed and a further 6% who claimed that a new condition had developed which was attributed to their caring role.

Further to this, the General Household Survey (2000) found that over 80% of carers claimed that their caring role had led to damage to their health.

<sup>Y</sup> Hirst, M., 2004, 'Hearts and Minds: the health effects of caring', Carers UK, London

<sup>Z</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>AA</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre



Clearly, many of the illnesses cited by carers may result in serious consequences in the event that they are not appropriately managed. Carers' Centres provide support to carers that helps them to access appropriately the health and other services needed to ensure that the impact on their physical health of caring is mitigated.

The table below shows the assumptions and calculation of the proxy used to measure the damage avoided from managing medical conditions in carers:

Physical health - carer	Assumption	Calculation	Evaluated benefits/gains (£)
Average annual cost per patient for a two week rehabilitation care episode	4,254		
Cost per week of short term LA residential care	1,067		
Deduction to cost of LA care	-50%	534	
Number of weeks of carer rehabilitation care	2		
<b>Total cost arising from physical health issues per annum (£)</b>			<b>5,321</b>

It is assumed that a carer with a deteriorating medical condition may require admission to either hospital or to a rehabilitation unit. For the purposes of this exercise, it is assumed that a carer would require a stay of average length (two weeks) at an NHS hospital-based rehabilitation ward, at an annual cost of £4,254<sup>BB</sup>.

As noted above, in the event that a carer requires treatment of this nature, health and social services in fact have two patients to care for, as the person who is cared for will also require a temporary residential care place. We have taken the cost per week of a short-term stay in a LA residential care home for older people of £1,067 as a measure of this cost<sup>CC</sup> less a deduction of 50% in order to ensure the assumed value of residential care takes into account the lower cash cost to the Local Authority of using a private facility compared to its own.

Whilst this 'proxy' reflects the research data in respect of typical patient stay durations, it should be noted that this has only been applied to a low proportion of the population of carers and people they care for.

## Reduced risk of physical injury to the carer

70% of carers surveyed by Carers Scotland reported suffering back or shoulder pain<sup>DD</sup>, and SPRU notes that "injuries sustained while lifting and moving the person they are looking after also limit or prevent the carer's ability to provide care and fulfil their other roles". The NHS' carers' survey found that 11% of carers reported physical strain<sup>EE</sup>.

Carers' Centres provide carers with the support they need to negotiate with LAs for lifting equipment to be provided, or for additional care staff to be provided to assist with lifting the person they care for. They also provide training in moving and handling practices to ensure that carers minimise the physical risks to themselves when providing physical assistance to the person they care for.

In the context of the research noted above and the Action Research group's belief that the most likely physical injury would be a back injury sustained while lifting, we have used the cost of treating such injury, as follows:

<sup>BB</sup> Curtis, L., 2010, Unit Costs of Health and Social Care 2010, PSSRU, University of Kent, Canterbury, at p.124

<sup>CC</sup> Curtis, L., 2010, Unit Costs of Health and Social Care 2010, PSSRU, University of Kent, Canterbury, at p.52

<sup>DD</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>EE</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

Physical injury risk - carer	Assumption	Calculation	Evaluated benefits/gains (£)
Cost of physiotherapy to rehabilitate patient with lower back pain	4,526		
Number of injuries per annum per carer affected in this way	1		
<b>Total cost of physiotherapist and A&amp;E cost (per annum)</b>			<b>4,526</b>

The Chartered Society of Physiotherapy ("CSP") estimated the cost of rehabilitating a patient with lower back pain to be £4,526<sup>FF</sup>. CSP sets this in the context of the alternative cost to the NHS of surgery of £7,830. Hence, the assumption used for this evaluation is believed to be prudent.

It is assumed that one episode of physiotherapy would be required per annum. This appears to be prudent, given that the carer is likely to be continuing to provide care during their rehabilitation (or relatively soon after surgery), therefore placing themselves at greater risk of a recurrence of the condition or of causing greater damage.

We also note that other costs may include the cost of Local Authority staff attending to carry out lifting while the carer is incapacitated, and, potentially the cost of a temporary placement in residential care while the carer recuperates following treatment. This would depend on the severity of the patient's condition, their age and weight and the physical ability of the carer. Given the wide range of variables in this context, we have not measured the potential cost of alternative care, but note that the above proxy represents the minimum expected economic value of the damage avoided by providing support to the carer.

## Improved carer ability to remain in employment

45% of carers surveyed by Carers Scotland indicated that they experience difficulties due to a low income, with 53% reporting reducing their expenditure on food and 60% on heating<sup>GG</sup>, both of which may result in negative impacts on physical health. This issue arises primarily because carers are often required to reduce their paid employment hours in order to meet their caring commitments. The issue raised by SPRU<sup>HH</sup> noted above of low confidence and self-esteem among the mental health issues faced by carers may also impact upon the ability of carers to remain in employment.

The NHS' carers survey in 2010 found that 39% of carers had given up employment due to their caring responsibilities and that 32% had reduced their hours<sup>II</sup>. It is concerning to note that this survey also found that only 19% were aware of their right to ask for flexible working. 10% of carers indicated that they would be keen to return to work when their caring responsibilities have reduced. 68% of carers that would seek a return to work indicated that flexible working arrangements would help them to return to the workplace.

Carers' Centres provide support to ensure that carers are receiving the welfare benefits to which they are legally entitled, but also provides support when negotiating their working hours with employers. Typically, an employer may not be responsive to the needs of the carer as their needs may not be commensurate with those of the business. By providing carers with robust arguments that support their case, Carers' Centres increase the likelihood that a carer will be able to maintain at least some hours of paid employment.

Carers themselves are typically keen to remain in employment for both financial and non-financial reasons, with 40% responding to Carers Scotland's survey that they believe that remaining in paid employment would improve their health and wellbeing<sup>JJ</sup>.

The table below shows the assumptions and calculations used to arrive at a proxy for this area:

<sup>FF</sup> CSP, 2005, Physiotherapy proves effective low cost alternative to back surgery, accessed at [www.csp.org.uk/director/press/pressreleases.cfm](http://www.csp.org.uk/director/press/pressreleases.cfm)

<sup>GG</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>HH</sup> Hirst, M., 2004, 'Hearts and Minds: the health effects of caring', Carers UK, London

<sup>II</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

<sup>JJ</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

Ability to maintain employment - carer	Assumption	Calculation	Evaluated benefits/gains (£)
Average per capita GVA (£ per annum) - UK full time average	19,977		
Working weeks per annum	46		
Hours per week (full time)	40		
Therefore UK average GVA per hour (£)		11	
Assumed working hours per week (if part time)	20		
Proportionate reduction avoided through effective support	50%	10	
Therefore reduction in working hours avoided per annum		460	
Therefore reduction in GVA avoided per annum			4,994

The latest available average per capita GVA for the UK of £19,977<sup>KK</sup> has been divided by an assumed 46 week working year (i.e. allowing for an assumed six weeks of holiday for a full time equivalent employee), and then by an assumed 40 hour week to derive an hourly GVA per employee of £11.

It is an implicit assumption of this model that a carer would not be able to maintain full time employment and fulfil the demands placed on them as a carer (i.e. they would, at most, be able to work part time, hence 20 hours of productive employment would be 'lost' in any case). It is therefore assumed that a properly supported carer may be able to work part-time (represented in the model above by a 20 hour week). Given that less than 25% of carers provide care for 20 hours or more per week<sup>LL</sup>, this is believed to be reasonable (i.e. a carer works for the equivalent of half a 40 hour working week as a carer, leaving half available for paid employment).

The alternative of an inadequately supported carer is assumed to be a 50% reduction in hours of paid employment (i.e. a ten hour reduction compared to a properly supported carer). The model therefore evaluates the impact of the ten hours of productive employment that would otherwise be lost.

The ten hours weekly reduction in paid employment avoided (i.e. the reduction that has been avoided through adequate support for the carer) is used to derive an annual economic damage avoided by improving support for carers of £4,994 (£11 x 10 hours x 52 weeks = £4,994). This appears to be a relatively prudent assumption, given that many carers give up paid employment altogether.

## Ability to return early to paid employment after care giving ceases

The period of caring is likely to cease for most carers either when the person they care for's condition has deteriorated such that they require an admission to residential care or upon death of the person they care for. Depending on the age of the carer, they may wish to return to paid employment.

The various mental and physical wellbeing issues identified above are likely to impact upon the carer's ability to make a return to paid employment or may affect the timescale in which such return is possible. For example, a carer with severe anxiety, depression, low self-esteem and poorly managed medical conditions is unlikely to be employable until these issues have been resolved. In many cases a resolution may be possible but would take a substantial amount of time.

In the long term a carer may suffer a wage penalty compared to the wider population as a result of giving up paid employment or reducing their hours. Dolan, Fujiwara and Peasgood (2010)<sup>MM</sup> found this penalty to be a gap of up

<sup>KK</sup> Source: Office for National Statistics

<sup>LL</sup> Hirst, M., 2004, 'Hearts and Minds: the health effects of caring', Carers UK, London

<sup>MM</sup> Dolan, P., Fujiwara, D. & Peasgood, T. (2010), 'The impact of the carer burden', unpub.

to 25%. The potential to reduce this long term penalty is excluded from the evaluation for prudence, as it may occur regardless of the level of support a carer receives.

By providing support to carers to manage physical and mental conditions, mitigating the risk of physical injury and providing training in key skills in areas such as IT, Carers' Centres provide a foundation upon which a carer may build to achieve a more rapid return to paid employment than would otherwise be possible. For some cases, it is likely that without this support, such return would never be possible. For prudence, this evaluation assumes that a return to paid employment would be achieved in any case, but that it is accelerated by appropriate support during care giving.

The table below shows the assumptions and calculations used to derive a financial proxy:

Ability to return to full-time employment early after care-giving ceases	Assumption	Calculation	Evaluated benefits/gains (£)
Average per capita GVA (£ per annum) - UK full time average	19,977		
Time otherwise taken to achieve an entry to the workplace (years)	2.5		
Discount rate	3.5%		
Annuity factor		2.35	
Delay to end of care giving (years)	4		
Discount factor		0.87	
Therefore productivity uplift per carer affected			40,990

It is assumed that a carer for whom this model applies would be seeking a return to full-time employment, hence the full average per capita GVA of £19,977 applies<sup>NN</sup>.

It is assumed that an unsupported carer would require a 2.5 year period to recover mentally and physically before entering paid employment or before they are able to find a position given that their skills may be out-of-date. Hence, a well-supported carer that has received training to update their skills is believed to be able to achieve an entry to the workplace 2.5 years earlier than an unsupported carer.

The present value of the annual GVA figure over a 2.5 year period is then calculated using a DCF model (see Appendix D) from which an annuity factor of 2.35 is derived. A discount rate of 3.5% has been used in this model, as it:

- ▶ Is consistent with the long term average inflation rate for the UK calculated over a twenty year period, per the Bank of England. The risks associated with the project are believed to be adequately accounted for by the use of prudent assumptions, hence the remaining factor in the changing value of future cash flows is broadly represented by the impact of inflation;
- ▶ Is consistent with typical 'risk free' rates of return, typically taken as the return on UK Government stock;
- ▶ Is the rate recommended for use in project appraisal the UK Treasury's Green Book (for projects lasting less than 30 years).

It is assumed that there is a delay of four years until care giving ceases. The majority (66%) of carers responding to Carers Scotland's survey had been caring for more than ten years<sup>OO</sup>. From our discussions with the Action Research group, we note that many carers that make contact with their local Carers' Centre do so after several years of trying to manage alone (typically because they had not been made aware that support was available). We

<sup>NN</sup> Source: Office for National Statistics

<sup>OO</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

have evaluated the gain in the above model on the basis that a carer received support from the sixth year of care giving, and that the care giving period will cease after ten years. Whilst carers may be called upon to fulfil their role for much longer periods (or shorter) this is believed to be broadly representative of a typical situation.

## Delay to admission to long term residential care for the person who is cared for

It is inevitable that many of the illnesses suffered by the person who is cared for will deteriorate such that an admission to permanent residential care is required. In other cases it may be that the carer ceases to be capable of handling the situation due to a deterioration in their own physical or mental wellbeing. In such situations local services have a twofold set of issues: first, the costs of treating the carer and second, the cost of replacing the work of the carer with a statutory service (typically a care home).

A Randomised Control Trial study in the USA<sup>PP</sup> found that carers of patients with Alzheimer's disease who received support including six sessions of individual and family counselling over a ten year period were likely to remain in care at home (i.e. with the family carer) for 557 days (i.e. 1.5 years) longer than carers who did not receive this support. Carers' Centres provide more intensive interventions to support carers to access appropriate statutory services both for themselves and the cared for; they also provide more intensive personal support for the carer (given that the RCT discussed above involved only six counselling sessions over a ten year period). We also note that Alzheimer's may be more likely to lead inevitably to residential care than other conditions that a cared for person may suffer. Hence, it appears to be reasonable to conclude that Carers' Centres may have a more significant impact in delaying care home admission than the RCT suggests for support given to carers.

Carers' Centres provide support for the carer, described in detail above, that allows them to maintain their provision for as long as possible, thereby delaying the admission of the person who is cared for in cases where such admission is inevitable.

The table below shows the assumptions and calculations used to derive a financial proxy:

Cost of early entry to residential care - cared for person	Assumption	Calculation	Evaluated benefits/gains (£)
Cost per week of LA residential care	986		
Deduction to care cost to apply	-50%	493	
Number of weeks per annum	52		
Total cost of residential care avoided per annum		25,636	
Delay before admission in the absence of support (years)	1		
Deferral to admission possible with properly supported carer	4		
Discount rate	3.5%		
Annuity factor		2.80	
Discount factor		0.97	
Avoided cost of early admission to residential care			69,394

The weekly cost of a long-term placement in an LA residential care home of £986<sup>QQ</sup> may be used to derive an annual cost of £51,272 (i.e. £986 x 52 weeks). This has been reduced by 50% for prudence in order to account for the lower cash cost of Local Authorities of using a private care facility rather than their own.

<sup>PP</sup> Mittelman, M. et al. (1996), 'A Family Intervention to Delay Nursing Home Placement of Patients with Alzheimer Disease: A Randomized Controlled Trial', Journal of the American Medical Association

<sup>QQ</sup> Curtis, L., 2010, Unit Costs of Health and Social Care 2010, PSSRU, University of Kent, Canterbury, at p.52

It is assumed that, in the absence of support for the carer, an admission to long-term residential care would be required one year after the carer is referred to the Carers' Centre (assumed for the purposes of this evaluation to be several years after caring commenced – see above). With appropriate support in place, it is assumed that a carer may be able to continue to provide care for a further four years (i.e. a delay in admission to residential care of three years).

A DCF model (see Appendix D) is used to calculate an annuity factor for a three year period (4 years with support less one year without support), and a discount factor is calculated to account for the one year delay for which the carer could continue in any case.

Hence, a value of damage (i.e. the additional cost to the state of providing residential care) avoided as a result of support for the carer is calculated as £138,788 ( $£25,636 \times 2.80 \times 0.97 = £69,394$ ).

## Reduced risk of temporary care placement breakdown

The NHS' carers' survey (2010)<sup>RR</sup> found that 42% of carers have not had a break of at least two days since they started caring.

For some carers, a build-up of stress (or other mental health issues – see above) may lead to a temporary 'breakdown' of the caring relationship. In such situations, where it may be possible for the carer to resume their role, a temporary respite arrangement may be put in place.

This type of temporary, but severe, breakdown in the placement may be avoided by lower level but more frequent respite interventions. 57% of the responses to Carers Scotland's survey indicated that regular access to social or leisure activities would benefit them, and 31% indicated that they would like to undertake some form of learning<sup>SS</sup>.

In order to access such activities, if only for a brief period each week, carers need to be able to put in place an alternative form of provision for the person they care for. Carers' Centres provide support to carers to help them negotiate such alternative care provision such that they are able to have a brief period of respite from time to time. This may include the use of technology such as a telecare service or a Local Authority carer. There may be an incremental cost associated with such provision, which is considered below as part of the evaluation of a financial proxy for displacement.

It is felt to be likely that the cost of providing a brief period of respite at regular intervals for the carer will be outweighed by the damage avoided by mitigating the risk of a temporary (or worse, permanent) breakdown in the caring relationship. The table below shows the assumptions and calculations used to derive a proxy:

Risk of care breakdown leading to temporary residential care placement	Assumption	Calculation	Evaluated benefits/gains (£)
Cost per week of short term LA residential care	1,067		
Deduction to apply to care cost	-50%	534	
Number of weeks per annum	6		
Total cost of residential care avoided per annum			3,201

The cost per week of short term LA residential care of £1,067<sup>TT</sup> is multiplied by an assumed respite period of six weeks. This assumption is based on the results of Action Research group discussion on the likely time that would be required for a carer to recover in the event of a serious, but remediable, breakdown. This has been reduced by

<sup>RR</sup> NHS Information Centre Social Care Team (2010), 'Survey of Carers in Households 2009/10', London, NHS Information Centre

<sup>SS</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>TT</sup> Curtis, L., 2010, Unit Costs of Health and Social Care 2010, PSSRU, University of Kent, Canterbury, at p.124

50% for prudence to reflect the lower cash cost to Local Authorities of using private care facilities rather than their own.

Failure to provide such respite may pose severe risks for both carer and person they care for, hence failure to provide an emergency respite care place might create even more significant issues. It is, therefore, assumed, for prudence, that provision would be offered at this stage rather than considering more serious (and costly) consequences of failure to address the breakdown at an earlier stage.

## Reduced risk of a young carer being NEET at age 20 to 24

At the time of writing, around 20% of all people aged 20 to 24 were unemployed. This compared to a rate of 40% (NEET for more than six months) to 75% (NEET for any period) for those that were young carers<sup>UU</sup> according to the Audit Commission, and Dearden and Becker (2000a)<sup>VV</sup> found that of 60% for young carers are likely to be NEET at age 20 to 25. Young carers face many challenges that would be daunting for an adult, and that may result in them losing the time simply to be a child. Other consequences of the pressures that they face at home may be that they might be unable to find time to do homework or that the burden of caring makes them too tired to engage effectively in lessons. In particular, feelings of isolation and mental distress that are noted above for adults may have long-term consequences for a young carer.

The issues identified by Wadsworth (2008)<sup>WW</sup> indicate that the majority of young carers are either not in employment after they leave school or experience significant disadvantage when applying for jobs due to poor qualifications or poor school attendance records, with over a quarter of young carers leaving school with no GCSEs. This, combined with Dearden and Becker's finding that 60% of young carers are likely to be NEET at age 20 to 25, suggests that the propensity of young carers to suffer long term economic disadvantage in later life is high in the majority of cases.

Such issues may lead to a failure to engage with education or to a failure to complete effectively key psychological developmental phases from their childhood. By providing support and helping to ensure that young carers have opportunities for respite and to engage effectively in school, Carers' Centres reduce the risk that a young carer will go on to disengage and therefore underperform educationally.

The table below shows the assumptions and calculations used to derive a proxy:

Damage arising from being NEET at age 20 to 24	Assumption	Calculation	Evaluated benefits/gains (£)
Assumed annual productivity lost	13,624		
Assumed annual Jobseekers Allowance	2,696		
Annual economic damage during NEET period		16,320	
Discount factor	3.5%		
Duration (age 20 to 24)	4		
Annuity Factor		3.67	
Economic damage from age 20 to 24			59,945
Present Value of long term wage penalty suffered due to underachievement*			45,000
<b>Total damage from being NEET at age 20 to 24</b>			<b>104,945</b>

\*Assumes NEETs are subsequently employed at age 24

<sup>UU</sup> Source: Audit Commission (2010)

<sup>VV</sup> Dearden and Becker, 2000a), Growing up Caring – Vulnerability and Transition to Adulthood

<sup>WW</sup> Wordsworth, S. (2008), 'Young Carers Report', unpub.



The assumptions used above are in line with the work of the Prince's Trust on the economic damage caused by youth exclusion in the UK. This is an annually updated report published by the Prince's Trust, and we have used the 2011 edition for the purposes of this evaluation.

The assumed annual productivity lost is calculated by the Princes Trust using the average weekly wage for a person aged 20 to 24, which equates to £13,624 per annum<sup>xx</sup>. The rationale for the use of wages rather than a measure of economic productivity is that the group of young people that is at greatest risk of disaffection is felt to be more likely to enter the workplace at below average productivity. The figure used represents a 31.8% discount to the national average per capita GVA for all age groups. Hence, this appears to be a prudent, but reasonable assumption.

The assumption for the annual cost of Jobseekers Allowance is derived from the weekly rate of £51.85, being the current weekly rate for 16 to 24 year-olds<sup>yy</sup>.

These economic impacts occur over a four year period, hence a DCF model is used to calculate the present value of the future gains, using a discount rate of 3.5% (see above).

In addition to the costs associated with being NEET between ages 20 and 24, we have also considered the Prince's Trusts work on the long-term wage penalty that arises as a result of being unemployed at this age. Research carried out indicates that a long term wage penalty of at least 10%<sup>zz</sup> is observed, amounting to £45,000 on average over the life of an individual.

The evaluation of this impact of £104,945 is believed to be prudent, as a significant proportion of the value derived between age 20 and 24 is subject to a discount compared to the national average productivity, and it ignores several other outcomes linked to being NEET, particularly the increased incidence of crime.

It is felt that for the purposes of this evaluation it would be a step too far to assume, (and there is no clear evidence to support), a link between being a young carer and future tendencies towards criminal activity, hence this aspect of the Prince's Trust's work has been excluded from the evaluation.

## Evaluating displacement

In many cases, the work of a Carers' Centre involves 'signposting' carers towards statutory services to which they are entitled in any case, hence there is no incremental cost to the State as a result of the increased engagement. In fact, it may be argued that if a service is under-utilised then the funding for it has, in fact, been wasted. Hence, ensuring that a service is appropriately used may be viewed as increasing efficiency.

However, we note that some of the specific support packages that are put in place for carers involve additional services that may not ordinarily be available from a local health and social care services, which might be viewed as creating an incremental cost (i.e. displacement).

In order to estimate displacement, we have used an unpublished report prepared by Newcis based on a series of case studies on interventions to support carers with services to address issues similar to those for which proxies have been developed above. Interventions put in place for these case studies include provision of weekly respite time, referral for assessments, counselling and training in specific needs related to the person who is cared for's condition.

The outcomes of these case studies showed that interventions with an incremental cost of £485 to £500 over a six month period achieved positive outcomes in terms of:

- ▶ Improved carer health;

<sup>xx</sup> McNally, S. & Telhaj, S., 2010, The cost of Exclusion: Counting the cost of youth disadvantage in the UK, Prince's Trust, London

<sup>yy</sup> Source: [http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Employedorlookingforwork/DG\\_10018757](http://www.direct.gov.uk/en/MoneyTaxAndBenefits/BenefitsTaxCreditsAndOtherSupport/Employedorlookingforwork/DG_10018757)

<sup>zz</sup> McNally, S. & Telhaj, S., 2010, The cost of Exclusion: Counting the cost of youth disadvantage in the UK, Prince's Trust, London, p.8

- ▶ Carer able to continue paid employment or carer has now returned to paid employment; and
- ▶ Reduced carer stress and anxiety.

These outcomes are comparable to those measured by the proxies shown earlier in this Appendix, hence we have taken a cost of £500 per six months (i.e. £1,000 per annum per carer) as the value of the incremental cost of provision for carers. This displacement has been deducted for all carers in the case study evaluation models (see Appendix C)

# C. Detailed case study evaluation models used

## Background and methodology

The proxies used to measure key life course outcomes shown in Appendix B have been used as the foundation for a series of case study models. The rationale for this is that a review by the Action Research group of real life case studies highlighted that similar themes arose for all types of carer, notably mental and physical wellbeing, risk of physical injury, ability to sustain paid employment and ability to return to paid employment when caring ceased.

Rather than derive a separate set of proxies for each case study, which would risk being open to the accusation of 'spurious accuracy' given that the proxies used are firmly grounded in data and research to the greatest extent possible, we have asked the Action Research group to assign a probability to each proxy. The probabilities are intended to reflect the risk that a carer would experience the damage represented by each proxy in the absence of support.

Assumptions are made on the length of time for which each proxy may apply: some will be annually recurring during the period of caring, others will apply for a period after caring ceases. The present values of recurring gains are then derived using a Discounted Cash Flow approach.

The case studies used in this evaluation are:

- ▶ Young carer;
- ▶ Carer in paid employment;
- ▶ Parent carer of minor child;
- ▶ Parent carer of adult son/daughter; and
- ▶ Retired carer of spouse/partner.

An evaluation is thus derived for each case study, multiplied by the number of carers that fall within these categories based on the management information system records of the five Carers' Centres covered in this evaluation. These evaluations are then combined (after deductions for deadweight and alternative attribution) to give a total evaluation. This in turn is then divided by the number of carers brought into the case studies in total to present a weighted average evaluation per carer that can be used to extrapolate the results from these case studies to cover the wider carer population at the five centres. Given that the case studies selected cover approximately 75% of newly registered carers (i.e. 3,794 out of 4,994 fit into the five case study categories), it is felt that the weighted average derived provides a reasonable reflection of the gains for those carer relationships not included.

## Approach to internal attribution of Carers' Centre activities

Having arrived at an external evaluation (i.e. the evaluated gains/benefits from the perspective of beneficiaries and other external stakeholders), the scope of this project included deriving a value for certain specified areas of work within the Carers' Centre. The areas selected for evaluation are listed below:

- ▶ Drawing carers in;
- ▶ Information provision;
- ▶ Learning and development; and
- ▶ Carer involvement.

Our aim for the case studies has been to derive a 'holistic' evaluation that reflects the added value derived from these services being available from a single source. Hence, our summary includes attributions to 'other services' not listed above, and a premium to reflect the value that is added by more joined-up provision from a single source.

The approach to this attribution model has been to assign a percentage to each of the areas that reflects the Action Research group's collective view on their relative importance to achieving the outcomes shown in the evaluation.

From an external review perspective, this attribution does not alter the total value, but it may be useful to illustrate the return generated by specific areas of work from an internal perspective.

Our aim has been to create a robust evaluation model that can be applied with minimal adjustment to other Carers' Centres, and this we believe to have been accomplished by the approach described above. However, we note that Carers' Centres may have different areas of strategic focus for their community such that the relative importance of the areas of work listed above may vary from centre to centre. Accordingly it would be important (from an internal perspective) to review the assumptions made on the attribution of the evaluated gains/benefits to each area of work to ensure it fits with the relevant centre.

This attribution model does not impact on the view that an external observer would take of the value to society of the work of a Carers' Centre, and as such could be viewed as an 'optional' additional stage of the process in the event that a centre does not wish to take the evaluation further than deriving a value in total.

## Results of the case study models

### Young carer

The table below shows the evaluation of the total damage that may be avoided from supporting young carers at the five centres:

Case study illustration - young carer	Assumption	Number of stakeholders affected	Evaluated benefits/gains per capita (£)	Evaluated benefits/gains (£)
Number of carers supported	570			
Proportion that would otherwise have mental health issues	75%	428	6,951	2,973,063
Proportion that would otherwise have physical health issues	10%	57	5,321	303,455
Proportion that would otherwise suffer physical injury	5%	29	4,526	129,058
Proportion that would otherwise reduce their working hours	0%	-	4,994	-
Proportion that would otherwise have a temporary breakdown during the year	5%	29	3,201	91,276
Less: additional cost of engagement with services (displacement) if applicable				(570,296)
<b>Total evaluated benefits per annum</b>				<b>2,926,555</b>
Average length of care-giving (years)	5.0			
Discount rate	3.5%			
Annuity factor		4.52		
<b>Value of support to carers during care-giving period</b>				<b>13,213,549</b>
Proportion that would return early to full-time work	0%	-	40,990	-
Proportion of young carers that would otherwise be NEET at age 20 to 24	60%	342	104,945	35,909,982
<b>Total value (carer's perspective)</b>				<b>49,123,531</b>
Proportion of cared-for that would otherwise enter residential care earlier	20%	114	69,394	7,915,026
<b>Value before deduction for those that continue to suffer these outcomes</b>				<b>57,038,557</b>
Deduction for those that continue to suffer outcomes	50%			(28,519,279)
<b>Total value (carer and cared-for perspective)</b>				<b>28,519,279</b>

The probabilities assigned to each proxy for this model have been derived based on internal consultation on the likelihood of each outcome occurring for a young carer, as well as a review of published research by the project representative responsible for young carers.

Of particular note are the following:

- ▶ A probability of 0% has been assigned to the avoided reduction in working hours and early return to work proxies, given that this is covered by the evaluated damage of being NEET;
- ▶ The assumed probability of being NEET of 60% is based on research by Dearden and Becker (2000a) that showed 60% of young carers would be expected to be NEET at age 20 to 25;
- ▶ A relatively high probability of mental health issues arising has been assumed (75%). This is consistent with the findings of Carers Scotland's research and with specific work that has been done on outcomes for young carers which showed that<sup>AAA</sup>:
  - ▶ 17% feel depressed or unhappy a lot of the time;
  - ▶ 67% sometimes feeling depressed or unhappy;
  - ▶ 33% feel stressed and 40% feel worried a lot; and
  - ▶ 63% feel stressed and 57% feel worried sometimes.
- ▶ Other proxies have relatively low probabilities assigned, which is believed to be reasonable and prudent given that a child is felt to be less likely to be susceptible to medical conditions or physical injury than an older carer;
- ▶ It is assumed that in the absence of support for the carer, 20% of the people who are cared for would enter residential care after one year (see Appendix B). In the event of a breakdown in caring, other family members might be called upon to provide some support for the young carer. However, we note that if other family members were available in this way, it is more likely that they would be given caring responsibility than a child from the outset. On that basis, this assumption appears to be prudent.
- ▶ A deduction of 50% is made to the total to reflect the probability that despite the work of the Carers' Centre, some of the outcomes that have been modelled as being avoided may occur in any case (albeit these situations may be more effectively managed with support from the Carers' Centre). The model above is based on externally sourced research on the incidence of negative outcomes among carers, and it reflects the benefits that would be achieved in the event that the entire population of carers served by the five centres was entirely lifted out of such conditions (e.g. if all 75% were to avoid mental health issues). Clearly, this is highly unlikely to be the case, although it is to be expected that most carers will benefit from at least one of the above outcomes. The deduction of 50% is not, therefore, to be read as an assumption that 50% of carers derive no benefit from the service they receive. Rather, it is intended to reflect that some carers may derive more limited benefits due to the nature of the condition of the person who is cared for or their own circumstances over which the Carers' Centre has little or no control.

Displacement is accounted for as an annual deduction of £1,000 per carer per annum (see Appendix B). This is felt to account for the average incremental costs of accessing additional services either by the carer or on behalf of the person who is cared for. This is consistent with unpublished work we have been given access to from North East Wales Carers Information Service, which was produced in 2009.

The NHS' carers survey (2010)<sup>BBB</sup> highlights that 73% of carers had been caring for up to ten years, with 51% having cared for up to five years and 24% having cared for between five and ten years. A significant minority (27%) had cared for over ten years. In time, it is likely that some of the 24% that have cared for between five and ten years will reach and exceed the ten year mark. The Carers Scotland report<sup>CCC</sup> found that 66% of carers had been caring for over ten years. There is some uncertainty around this research, as it focuses on carers who are still caring, and does not therefore conclusively show an average for how long they will ultimately be caring for. The impact of this is that the length of care-giving is potentially understated by the research.

<sup>AAA</sup> Wordsworth, S. (2008), 'Young Carers Report', unpub.

<sup>BBB</sup> The NHS Information Centre Social Care Team (2010) 'Survey of Carers in Households 2009/10', London, NHS

<sup>CCC</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

For young carers, it is assumed that the annually recurring gains last for an average length of care-giving of five years. This implicitly assumes that caring has been going on for a number of years before the carer was identified (which we understand is typically the case for most new contacts), and that five years of caring remain before the person who is cared for's condition deteriorates such that they must be admitted to residential care. In the case of a young carer, this is likely to be prudent given that they are more likely to be physically able to continue caring for a long period of time into adulthood. However, it must be considered that the condition of the person who is cared for is a more significant factor in the timing of a potential future entry to residential care than the ability of the carer, hence it appears to be reasonable and, indeed, prudent to assume a period of five years.

The rationale for the use of a discount rate of 3.5% is discussed above in Appendix B. Notes on Discounted Cash Flow methodology are provided at Appendix D.

Deductions for deadweight and alternative attribution are discussed later in this Appendix.

## Carer in paid employment

The table below shows the evaluation of the total damage that may be avoided from supporting carers that are in paid employment:

Case study illustration - carer in paid employment	Assumption	Number of stakeholders affected	Evaluated benefits/gains per capita (£)	Evaluated benefits/gains (£)
Number of carers supported	732			
Proportion that would otherwise have mental health issues	80%	585	6,951	4,068,442
Proportion that would otherwise have physical health issues	40%	293	5,321	1,557,217
Proportion that would otherwise suffer physical injury	50%	366	4,526	1,655,696
Proportion that would otherwise reduce their working hours	40%	293	4,994	1,461,592
Proportion that would otherwise have a temporary breakdown during the year	5%	37	3,201	117,099
Less: additional cost of engagement with services (displacement) if applicable				(731,638)
<b>Total evaluated benefits per annum</b>				<b>8,128,409</b>
Average length of care-giving (years)	5.0			
Discount rate	3.5%			
Annuity factor		4.52		
<b>Value of support to carers during care-giving period</b>				<b>36,700,192</b>
Proportion that would return early to full-time work	0%	-	40,990	-
Proportion of young carers that would otherwise be NEET at age 20 to 24	0%	-	104,945	-
<b>Total value (carer's perspective)</b>				<b>36,700,192</b>
Proportion of cared-for that would otherwise enter residential care earlier	20%	146	69,394	10,154,248
<b>Total value (carer and cared-for perspective)</b>				<b>46,854,440</b>
Deduction for those that continue to suffer outcomes	50%			(23,427,220)
<b>Total value (carer and cared-for perspective)</b>				<b>23,427,220</b>

The probabilities assigned to each proxy for this model have been derived from the incidence of each outcome based on feedback from the Action Research group. Where possible, this has been compared to data from published research on the incidence of these outcomes among carers (see below).

Of particular note are the following:

- ▶ The rates of mental and physical illness have been assumed based on published research from Carers Scotland, less adjustments for prudence. The actual rates found indicate that 86% of carers reported suffering from stress, anxiety and depression and 42% reported a serious medical condition that had commenced after they began caring<sup>DDD</sup>;
- ▶ The rate of physical health issues of 40% is felt to be prudent in light of the findings of the NHS carers survey (2010) that 52% of carers reported that their caring role had negatively affected their health (Carers Scotland reported that 96% of carers had experienced a negative health impact due to caring);
- ▶ The rate of physical injury of 50% is believed to be prudent in light of the findings of Carers Scotland that 70% of carers report back or shoulder pain<sup>EEE</sup>;
- ▶ The proportion of carers that would reduce their working hours of 40% is believed to be prudent, in light of that fact that many of these carers are likely to have been full time before caring commenced (the NHS carers survey found that 39% of carers had left paid employment altogether and that 32% had reduced their employment hours). As noted above, 40% of carers responded that they believe a return to work would improve their health and wellbeing<sup>FFF</sup>;
- ▶ It is assumed that in the absence of support a carer may reach a point at which their own mental and physical wellbeing has been impaired to the extent that they require a break before they are able to continue as a carer. It is assumed that 5% of care placements may reach this point without adequate support during the course of a given year;
- ▶ It is implicitly assumed that all of these carers maintain some level of working, hence the early return to work model is not relevant in this case (i.e. an assumption of 0% is used);
- ▶ The model that considers the impact of being NEET at age 20 to 24 is not applicable given that these carers are implicitly assumed to be in work, hence the 0% assumption; and
- ▶ It is assumed that in the absence of support for the carer, 20% of the people who are cared for would enter residential care after one year (see Appendix B).
- ▶ A deduction of 50% is made to the total to reflect the probability that despite the work of the Carers' Centre, some of the outcomes that have been modelled as being avoided may occur in any case (albeit these situations may be more effectively managed with support from the Carers' Centre). The model above is based on externally sourced research on the incidence of negative outcomes among carers, and it reflects the benefits that would be achieved in the event that the entire population of carers served by the five centres was entirely lifted out of such conditions (e.g. if all 75% were to avoid mental health issues). Clearly, this is highly unlikely to be the case, although it is to be expected that most carers will benefit from at least one of the above outcomes. The deduction of 50% is not, therefore, to be read as an assumption that 50% of carers derive no benefit from the service they receive. Rather, it is intended to reflect that some carers may derive more limited benefits due to the nature of the condition of the person who is cared for or their own circumstances over which the Carers' Centre has little or no control.

Displacement is accounted for as an annual deduction of £1,000 per carer per annum (see Appendix B).

### ***Duration of benefits***

As is noted earlier in this appendix, the majority of carers surveyed by the NHS (51%) had been caring for up to five years and that 73% had been caring for up to ten years, although the survey for Carers Scotland found that 66% had been caring for over ten years. We also note above that this research covers carers who are still caring and is therefore likely to be an understatement of the total duration of care-giving (which is, clearly, unknown to them). On the basis of this finding, it was felt to be reasonable to use a duration of five years as the period over which a carer may be expected to continue their role after their initial contact with a Carers' Centre.

The five year assumption implicitly assumes that caring has been going on for a number of years before the carer was identified, and that five years of caring remain before the person who is cared for's condition deteriorates such that they must be admitted to residential care (or the carer ceases to be able to continue). Feedback from the

<sup>DDD</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>EEE</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow

<sup>FFF</sup> Carers Scotland, 2011, 'Sick, tired and caring: the impact of unpaid caring on health and long term conditions', Carers Scotland, Glasgow



Action Research group was that early identification is becoming a key focus of Carers' Centres, and that this period prior to identification is likely to be reducing in length. It would not, however, be unexpected to see a carer make contact after struggling alone for around five years. The five year duration of savings assumption is therefore consistent with a maximum time caring of up to ten years (i.e. five years pre-identification plus five years post identification), which is broadly consistent with the typical duration of caring shown from the NHS carers survey.

### Discount rate

The rationale for the use of a discount rate of 3.5% is discussed above in Appendix B. Notes on Discounted Cash Flow methodology are provided at Appendix D.

Deductions for deadweight and alternative attribution are discussed later in this Appendix.

## Parent carer of minor child

The table below shows the evaluation of the total damage that may be avoided from supporting parents caring for children under the age of 18:

Case study illustration - parent carer for minor child	Assumption	Number of stakeholders affected	Evaluated benefits/gains per capita (£)	Evaluated benefits/gains (£)
Number of carers supported	957			
Proportion that would otherwise have mental health issues	75%	718	6,951	4,988,203
Proportion that would otherwise have physical health issues	40%	383	5,321	2,036,545
Proportion that would otherwise suffer physical injury	50%	478	4,526	2,165,336
Proportion that would otherwise reduce their working hours	40%	383	4,994	1,911,485
Proportion that would otherwise have a temporary breakdown during the year	25%	239	3,201	765,714
Less: additional cost of engagement with services (displacement) if applicable				(956,843)
<b>Total evaluated benefits per annum</b>				<b>10,910,439</b>
Average length of care-giving (years)	5.0			
Discount rate	3.5%			
Annuity factor		4.52		
<b>Value of support to carers during care-giving period</b>				<b>49,261,205</b>
Proportion that would return early to full-time work	25%	239	40,990	9,805,198
Proportion of young carers that would otherwise be NEET at age 20 to 24	0%	-	104,945	-
<b>Total value (carer's perspective)</b>				<b>59,066,403</b>
Proportion of cared-for that would otherwise enter residential care earlier	10%	96	69,394	6,639,914
<b>Total value (carer and cared-for perspective)</b>				<b>65,706,317</b>
Deduction for those that continue to suffer outcomes	50%			(32,853,159)
<b>Total value (carer and cared-for perspective)</b>				<b>32,853,159</b>

The probabilities assigned to each proxy for this model have been derived from the incidence of each outcome based on feedback from the Action Research group. Where possible, this has been compared to data from published research on the incidence of these outcomes among carers (see below).

Of particular note are the following:

- ▶ The rationales for probabilities assigned to mental health, physical health, physical injury and reduction to working hours are similar to those discussed above for carers in paid employment;
- ▶ It is assumed that 25% of care placements would break down during the year in the absence of support. This is felt to be reasonable, based on the evidence of real life case studies reviewed in the course of this project which highlight the additional emotional burden placed on parents caring for young children;
- ▶ It is assumed that 25% of parent carers who receive appropriate support will be able to return to full time employment earlier than would otherwise be possible when caring ceases (either due to death or admission to residential care of the person who is cared for). Given that parents are likely to be of an age at which paid employment would be expected, this does not appear to be unreasonable.
- ▶ It is assumed that, in the absence of support for the carer, 10% of people who are cared for would otherwise enter residential care after one year (as opposed to a four year delay – see Appendix B).
- ▶ A deduction of 50% is made to the total to reflect the probability that despite the work of the Carers' Centre, some of the outcomes that have been modelled as being avoided may occur in any case (albeit these situations may be more effectively managed with support from the Carers' Centre). The model above is based on externally sourced research on the incidence of negative outcomes among carers, and it reflects the benefits that would be achieved in the event that the entire population of carers served by the five centres was entirely lifted out of such conditions (e.g. if all 75% were to avoid mental health issues). Clearly, this is highly unlikely to be the case, although it is to be expected that most carers will benefit from at least one of the above outcomes. The deduction of 50% is not, therefore, to be read as an assumption that 50% of carers derive no benefit from the service they receive. Rather, it is intended to reflect that some carers may derive more limited benefits due to the nature of the condition of the person who is cared for or their own circumstances over which the Carers' Centre has little or no control.

Displacement is accounted for as an annual deduction of £1,000 per carer per annum (see Appendix B).

The rationale for the use of a duration of five years for these benefits is discussed earlier in this appendix.

The rationale for the use of a discount rate of 3.5% is discussed above in Appendix B. Notes on Discounted Cash Flow methodology are provided at Appendix D.

Deductions for deadweight and alternative attribution are discussed later in this Appendix.

## **Parent carer of adult son/daughter**

The table below shows the evaluation of the total damage that may be avoided from supporting parents caring for children over the age of 18:

Case study illustration - parent caring for adult son/daughter	Assumption	Number of stakeholders affected	Evaluated benefits/gains per capita (£)	Evaluated benefits/gains (£)
Number of carers supported	355			
Proportion that would otherwise have mental health issues	75%	266	6,951	1,851,593
Proportion that would otherwise have physical health issues	40%	142	5,321	755,954
Proportion that would otherwise suffer physical injury	50%	178	4,526	803,760
Proportion that would otherwise reduce their working hours	40%	142	4,994	709,533
Proportion that would otherwise have a temporary breakdown during the year	10%	36	3,201	113,691
Less: additional cost of engagement with services (displacement) if applicable				(355,175)
<b>Total evaluated benefits per annum</b>				<b>3,879,357</b>
Average length of care-giving (years)	5.0			
Discount rate	3.5%			
Annuity factor		4.52		
<b>Value of support to carers during care-giving period</b>				<b>17,515,498</b>
Proportion that would return early to full-time work	5%	18	40,990	727,927
Proportion of young carers that would otherwise be NEET at age 20 to 24	0%	-	104,945	-
<b>Total value (carer's perspective)</b>				<b>18,243,425</b>
Proportion of cared-for that would otherwise enter residential care earlier	20%	71	69,394	4,929,397
<b>Total value (carer and cared-for perspective)</b>				<b>23,172,823</b>
Deduction for those that continue to suffer outcomes	50%			(11,586,411)
<b>Total value (carer and cared-for perspective)</b>				<b>11,586,411</b>

The probabilities assigned to each proxy for this model have been derived from the incidence of each outcome based on feedback from the Action Research group. Where possible, this has been compared to data from published research on the incidence of these outcomes among carers (see below).

Of particular note are the following:

- ▶ The rationales for probabilities assigned to mental health, physical health, physical injury and reduction to working hours are similar to those discussed above for carers in paid employment;
- ▶ It is assumed that 10% of care placements would break down during the year in the absence of support. This is felt to be reasonable, based on the evidence of real life case studies reviewed in the course of this project and other unpublished research from Newcis evidence that indicates the importance of frequent respite for carers;
- ▶ It is assumed that 5% of parent carers will be able to return to full time employment earlier than would otherwise be possible when caring ceases (either due to death or admission to residential care of the person who is cared for). Given that this group of parents are caring for older children, it is felt to be reasonable to assume that a lower proportion will be of an age that they would wish to re-enter the workplace when care-giving ceases; and
- ▶ It is assumed that, in the absence of support for the carer, 20% of people who are cared for would otherwise enter residential care after one year (as opposed to a four year delay – see Appendix B).
- ▶ A deduction of 50% is made to the total to reflect the probability that despite the work of the Carers' Centre, some of the outcomes that have been modelled as being avoided may occur in any case (albeit these situations may be more effectively managed with support from the Carers' Centre). The model above is based on externally sourced research on the incidence of negative outcomes among carers, and it reflects the benefits that would be achieved in the event that the entire population of carers served by the five centres was entirely lifted out of such conditions (e.g. if all 75% were to avoid mental health issues). Clearly, this is highly unlikely to be the case, although it is to be expected

that most carers will benefit from at least one of the above outcomes. The deduction of 50% is not, therefore, to be read as an assumption that 50% of carers derive no benefit from the service they receive. Rather, it is intended to reflect that some carers may derive more limited benefits due to the nature of the condition of the person who is cared for or their own circumstances over which the Carers' Centre has little or no control.

Displacement is accounted for as an annual deduction of £1,000 per carer per annum (see Appendix B).

The rationale for the assumed duration of benefits of five years is discussed earlier in this Appendix.

The rationale for the use of a discount rate of 3.5% is discussed above in Appendix B. Notes on Discounted Cash Flow methodology are provided at Appendix D.

Deductions for deadweight and alternative attribution are discussed later in this Appendix.

## Retired carer of spouse/partner

The table below shows the evaluation of the total damage that may be avoided from supporting parents caring for their spouse/partner:

Case study illustration - retired carer of spouse/partner	Assumption	Number of stakeholders affected	Evaluated benefits/gains per capita (£)	Evaluated benefits/gains (£)
Number of carers supported	787			
Proportion that would otherwise have mental health issues	80%	629	6,951	4,373,731
Proportion that would otherwise have physical health issues	40%	315	5,321	1,674,068
Proportion that would otherwise suffer physical injury	60%	472	4,526	2,135,924
Proportion that would otherwise reduce their working hours	0%	-	4,994	-
Proportion that would otherwise have a temporary breakdown during the year	50%	393	3,201	1,258,855
Less: additional cost of engagement with services (displacement) if applicable				(786,538)
<b>Total evaluated benefits per annum</b>				<b>8,656,040</b>
Average length of care-giving (years)	5.0			
Discount rate	3.5%			
Annuity factor		4.52		
<b>Value of support to carers during care-giving period</b>				<b>39,082,472</b>
Proportion that would return early to full-time work	0%	-	40,990	-
Proportion of young carers that would otherwise be NEET at age 20 to 24	0%	-	104,945	-
<b>Total value (carer's perspective)</b>				<b>39,082,472</b>
Proportion of cared-for people that would otherwise enter residential care earlier	20%	157	69,394	10,916,205
<b>Total value (carer and cared-for person perspective)</b>				<b>49,998,677</b>
Deduction for those that continue to suffer outcomes	50%			(24,999,339)
<b>Total value (carer and cared-for perspective)</b>				<b>24,999,339</b>

The probabilities assigned to each proxy for this model have been derived from the incidence of each outcome based on feedback from the Action Research group. Where possible, this has been compared to data from published research on the incidence of these outcomes among carers (see below).

Of particular note are the following:

- ▶ The rationales for probabilities assigned to mental health, physical health and physical injury are similar to those discussed above for carers in paid employment;
- ▶ It is implicitly assumed that the retired carer does not wish to continue their paid employment, hence the assumption as regards reduction to working hours is set at 0%;
- ▶ It is assumed that 10% of care placements would break down temporarily during the year in the absence of support for the carer;
- ▶ Given the assumed retired status of the carer, the assumptions as regards early return to paid employment and being NEET at age 20 to 24 are set to 0%; and
- ▶ It is assumed that, in the absence of support for the carer, 20% of people who are cared for would otherwise enter residential care after one year (as opposed to a four year delay – see Appendix B).
- ▶ A deduction of 50% is made to the total to reflect the probability that despite the work of the Carers' Centre, some of the outcomes that have been modelled as being avoided may occur in any case (albeit these situations may be more effectively managed with support from the Carers' Centre). The model above is based on externally sourced research on the incidence of negative outcomes among carers, and it reflects the benefits that would be achieved in the event that the entire population of carers served by the five centres was entirely lifted out of such conditions (e.g. if all 75% were to avoid mental health issues). Clearly, this is highly unlikely to be the case, although it is to be expected that most carers will benefit from at least one of the above outcomes. The deduction of 50% is not, therefore, to be read as an assumption that 50% of carers derive no benefit from the service they receive. Rather, it is intended to reflect that some carers may derive more limited benefits due to the nature of the condition of the person who is cared for or their own circumstances over which the Carers' Centre has little or no control.

Displacement is accounted for as an annual deduction of £1,000 per carer per annum (see Appendix B).

The rationale for the assumed duration of benefits of five years is discussed earlier in this Appendix.

The rationale for the use of a discount rate of 3.5% is discussed above in Appendix B. Notes on Discounted Cash Flow methodology are provided at Appendix D.

Deductions for deadweight and alternative attribution are discussed later in this Appendix.

## Combined evaluation model

The table below shows the combination of the above case study models, the deductions for deadweight and alternative attribution applied (displacement being accounted for in the case study models – see above). It also shows the calculation of the weighted average benefits/gains per carer based on those case studies and the application of this to the wider population of newly registered carers and then to carers registered before 2010:

Summary evaluation	Total evaluated benefits/gains (£)	Deduction for deadweight (%)	Deduction for alternative attribution (%)	Benefits/gains due to carers centre (£)
Young Carer	28,519,279	10%	50%	11,407,711
Carer in paid employment	23,427,220	10%	50%	9,370,888
Parent carer of minor child	32,853,159	10%	50%	13,141,263
Parent carer of adult son/daughter	11,586,411	10%	50%	4,634,565
Retired carer for spouse/partner	24,999,339	10%	50%	9,999,735
<b>Total evaluated benefits/gains due to carers centres</b>				<b>48,554,163</b>
Number of carers included in the above evaluations			3,400	
<b>Therefore average benefits/gains per carer supported</b>				<b>14,279</b>
Total newly registered carers	4,745			
Proportion of value to recognise in year 1 of contact	60%			
<b>Therefore lifecourse gains for newly registered carers</b>				<b>40,651,113</b>
Other carers not accounted for above	22,542			
Gain to recognise for any year after initial referral	10%			
<b>Therefore gain to recognise for pre-existing carers</b>				<b>32,186,772</b>
<b>Therefore benefits/gains attributable across five centres</b>				<b>72,837,885</b>

### ***Deductions for deadweight and alternative attribution***

- ▶ **Deadweight:** It is assumed that, in the absence of any intervention, there may be minimal improvement to the situation of carers, in that some carers might be in a position, for example, to negotiate improvements in LA provision themselves. This is, however, felt likely to be the case only in exceptional circumstances, hence a relatively low deduction for deadweight of 10% is assumed.
- ▶ **Alternative attribution:** it is assumed that Carers' Centres act primarily in a role as facilitators by enabling carers to access the services they are entitled to and putting an effective case for enhanced provision. However, the Carers' Centres also recognise the valuable role played by the agencies they engage with in providing the additional support needed to deliver the gains shown above, hence a deduction of 50% is assumed.

The Carers' Centre representatives and The Trust believe that these deductions are a prudent reflection of the value of their work.

### ***Deriving an overall value***

#### ***Benefits from work with carers registered in 2010***

The total value of the case study models (after deductions for deadweight and alternative attribution) is divided by the number of carers included in the models to arrive at a weighted average (i.e. those models with higher numbers of carers have greater impact on the average) of £14,279 per carer supported (i.e. £48.6m ÷ 3,400 carers = £14,279).

To extrapolate this average across the whole population of newly registered carers (of which the case studies shown earlier represent 72%), we have multiplied the average gains of £14,279 by the total number of newly

registered carers across the five centres. This is then multiplied by 60%, being the assumed proportion of the benefits achieved that is to be attributed to the first year of contact. (i.e. £14,279 x 4,745 x 60% = £40.7 million).

This recognises the life course gains of carers registered in 2010 that related to that specific year. Gains associated with future years for this tranche of carers would be caught by the mechanism described below.

#### *Benefits from work with carers registered before 2010*

It is then necessary to evaluate the gains achieved in the lives of carers registered before 2010, but after deducting for attribution to the majority of the gains achieved to work done in the year of registration (for further detail on future application of this approach see §5.9 -5.14). For the purposes of this evaluation, it is assumed that 60% of the life course gain achieved is attributed to the initial work done to put appropriate support in place, and that 10% of the life course gain is attributed to each of four further years of gain.

For future years, in the event that a carer continues to care for more than five years, each subsequent year of caring is to be recognised at 10% of the life course value (for further detail on future application of this approach see §5.9-5.14).

The benefits achieved for carers registered before 2010 is therefore included at 10% of the life course benefits for carers registered during 2010 (i.e. 22,542 x £14,279 x 10% = £32.2m).

### **Total evaluated carer life course benefits for 2010**

Hence the total benefits evaluated for the five Carers' Centres for 2010 amounts to £72.8m (£40.6m relating to carers registered in 2010 plus £32.2m in relation to carers registered prior to 2010).

## **Attributing the total evaluation to areas of work**

The table below shows the assumed proportions of the evaluated gains due to the following areas of work:

- ▶ Drawing carers in (i.e. carer identification);
- ▶ Information and planning;
- ▶ Training and learning development;
- ▶ Carer involvement;
- ▶ 'Other services'; and
- ▶ A premium attached to the value of a holistic (rather than piecemeal) service.

Summary evaluation	Proportion of gains attributed from (%)	Proportion of gains attributed to (%)	Proportion of gains attributed consensus (%)	Benefits/gains due to each activity (£)
Drawing carer in	10%	20%	15%	10,925,683
Information and planning	25%	50%	38%	27,314,207
Training and learning development	10%	15%	13%	9,104,736
Carer involvement	10%	10%	10%	7,283,788
Other services	10%	15%	13%	9,104,736
Premium for holistic approach	10%	15%	13%	9,104,736
<b>Total</b>			<b>100%</b>	<b>72,837,885</b>

*\*Note total does not equal 100% due to rounding*



It has become clear from our work with the Carers' Centres that different geographical areas require different approaches. This is shown from the range of views on the relative weighting of the above areas of work as regards their relative importance in achieving the gains discussed in this report. This has no impact on the total gains evaluated, it merely reflects the different ways of achieving these gains. In order to reflect a consensus view across the five centres, we have used an average based on the range of attribution percentages provided by the five centres. The Action Research group has agreed that this represents a reasonable consensus view of the typical work of a Carers' Centre.

## Evaluating the commercial value of carer involvement

In addition to the above evaluation of the outcomes arising in the life course of the carer and person they care for, we have also identified that there is a value attached to the time spent by former carers acting to advise LAs on issues such as strategic planning of services. The impact of this work is that services in local areas are more likely to be user-friendly and accessible for carers, thereby improving the likelihood of achieving the positive outcomes reflected in the evaluations above.

However, the value of former carer time in providing such advice has not been included above. On the basis that without this advice strategic decision making might be less effective, it appears that carers that become involved in this way are effectively acting as consultants, but are not paid as such.

Typically, a junior public sector consultant may be expected to be charged out at a rate of c£1,000 per day (i.e. £133 per hour, assuming a 7.5 hour day). We have used this hourly rate together with an estimate of the number of hours spent by carers in an advisory capacity, as follows:

Value of carer involvement time	Assumption	Benefits/gains due to each activity (£)
Number of hours spent by carers at steering groups etc.	2,160	
Assumed hourly rate	133	
Alternative attribution	50%	
<b>Total</b>		<b>143,640</b>

Data provided by Carers' Centres that host or co-ordinate involvement in this way indicates that 2,160 hours of carer time were spent during 2010 on involvement with steering groups, focus groups or committees with the aim of influencing the quality and quantity of provision for carers.

In this model, we have attributed 50% of the gains to the carers themselves, given that the Carers' Centre acts as facilitator (i.e. the gain would not be achievable without them), but the carer's expertise and willingness make them equivalent to equal partners (i.e. a 50/50 share does not appear to be unreasonable). This evaluation is added separately into the overall total to avoid confusion with the life course analysis models.

## D. Discounted Cash Flow methodology

Our analysis takes into account, where necessary, the premise that the value of money changes over time. The value of future cash flows is subject to the risk that those cash flows will not in fact occur for any number of reasons.

For the purposes of this report, assumptions provided by the Carers' Centres have been taken to be reflective of any risks associated with the likelihood of benefits actually flowing to the stakeholder concerned. This leaves the risk that the value of the benefit will fluctuate due to economic factors that are beyond the control of The Trust or stakeholder. This can be measured using a long term average rate of inflation. Where necessary a discount rate of 3.5% has been used, which equates to the average rate of inflation in the UK measured over the past twenty years, per the Bank of England. It is also consistent with the discount rate typically used by the UK Government for project appraisal (for projects lasting for between 0 and 30 years)<sup>GGG</sup>

For benefits only during the year in which they are funded no discounting is used as both the funding and the benefit are released during the year and the timings are therefore already matched.

Where a benefit occurs in a future year, the value of the benefit is multiplied by a discount factor to allow comparison with the cost of funding. The discount factor is calculated using the formula below:

$$DF = \left( \frac{1}{1+r} \right)^t$$

Where:

- ▶ 'DF' is the discount factor by which a future benefit is multiplied to restate it in current terms;
- ▶ 'r' is the discount rate used; and
- ▶ 't' is the time, stated in years, between the date at which value is measured and the date at which the benefit is achieved.

To measure benefits that occur at a fixed value over a period of time, The Trust were asked to assume that any future benefits occur in the form of a constant annuity over a fixed period. The expected annual cash flow is then multiplied by an annuity factor to give the value in present day terms of the benefit. The annuity factor is calculated using a modified discount formula, as shown below:

$$AF = \left( \frac{1}{r} \right) \times \left[ 1 - \left( \frac{1}{1+r} \right)^t \right]$$

Where:

- ▶ 'AF' is the factor by which a constant annuity is multiplied in order to obtain the present value of that annuity over a given period of time;
- ▶ 'r' is the discount rate used; and
- ▶ 't' is the number of years the annuity is expected to occur over.

Where an annuity is to be deferred for a number of years (e.g. a project is being developed now but the savings will not be realised for several years), an annuity factor is used to calculate the present value of the incremental benefits in the future which is then multiplied by a discount factor to restate it in present day terms.

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<sup>GGG</sup> Lowe, J., 2008, Intergenerational wealth transfers and social discounting: Supplementary Green Book guidance, London, HM Treasury

## E. Example cases studies

A sample of case studies have been provided for inclusion with this report, with the permission of the carers concerned. Many of these stories are told in the carer's own words, and all have been anonymised to protect confidentiality.

### 'Sue' – extract from a speech

My name is Sue and I have been a carer for my son for 8 years, Jonathon was diagnosed at the age of 5 with Autism, Dyspraxia, speech and language delay and quite recently with severe dyslexia.

Diana asked if I would stand up here today and give a short speech on my journey as a carer.

The first thing that I realized when I sat down to write this speech was how difficult it was recalling the start of my journey. In order to survive, I had created a system of coping. I would literally forget what had happened the day before in order to make room and cope with the next one. Looking back it seems so long ago.

I had feelings of:

- ▶ Exhaustion, from the endless sleepless nights of night terrors, anxiety and bed wetting. And dealing with his behaviours.
- ▶ Being Unfocused during the day due to lack of sleep,
- ▶ Being Frustrated as I wasn't being listened to or heard by health visitors, or Doctors, or anyone in authority.
- ▶ I had to come to terms with my Childs condition. That somehow my son being disabled was my fault. And what future did we have?

I know I had feelings of,

- ▶ Isolation, I had a child that needed an extreme amount of looking after, with what society deemed anti-social behaviour, nearly all friends and family stayed away, they couldn't understand why Jonathon was the way he was. If we were out shopping and Jonathon touched someone inappropriately or just flipped out, they would look at me in horror and disgust, and mutter hurtful comments like, he needs a good smack or can't you control him?, or actually say that I was a useless mother. If I had the energy I may have said something back, but more often than not, I would go home and just cry. And eventually we stopped going out.
- ▶ My self esteem and confidence were completely, smashed to pieces. I had suicidal thoughts, because I felt that I just couldn't cope anymore.
- ▶ Depression set in, as I felt worthless and useless, my best, just wasn't good enough. I felt alone and Overwhelmed at having to function in a world that didn't accept my son for who he was. Or me, for caring for him.
- ▶ The most worrying part when I look back on this was that I believed this was all normal, to feel like this was part of my everyday life.

I was literally at my lowest point I had lost myself completely and was sinking fast. I found it extremely hard to ask for help as I felt; I had to keep it together. By this time I had joined Signal and had met some other frazzled parents which were a great source of knowledge someone from there told me about carers Lewisham. I didn't know much about them, but I found enough confidence on a good day to go and register my name and that was the first day in Feb 2004 that my journey to discover my potential started. Cathy C was the first support worker that I saw, she welcomed me in with open arms and started asking me about my situation and that was it the floodgates opened, I just couldn't contain it anymore. Someone actually cared about me, and what I was doing to help myself to continue as a carer. Once I had a searing pain in my head, my face was all tingly and the blood just drained out of my face I felt like I was going to die on the spot, it really scared me, I was in forest hill so I made me way over to

carers where I felt supported. I had a sit down, a cup of tea, Ulalee was talking to me and I burst into tears. It was all stress.

Other groups I had contact with seemed to concentrate on the person that you care for and I was always doing things, for my son, I forgot about me. Carers Lewisham helped me first by having a place to go, to talk to someone, to have a safe place where I would be understood and appreciated for what I do, I felt I could drop in if I was at breaking point and someone would be there I could talk to or even just sit and have a cup of tea and collect my thoughts in a safe caring environment.

I went on Art classes, and Jewellery making workshops, to get me out of the house, and mixing with people. I then went on self esteem workshops and laughter therapy, and had counselling. And joined in with the parent carers' group and the coffee mornings, to socialise.

Beverley then helped me in developing my Education and training. I had life coaching sessions where we set goals, I could actually see a future emerging for myself, since then, I became involved with my sons school, and have been a parent governor for 5 years.

I have been on a train the trainer course, counselling skills taster course, I felt that I had grown in confidence so much that Beverley suggested that I might like to do some voluntary work at Carers which I started to do last September, I started in reception, and was able to run six workshops on jewellery making, arts and crafts and handmade cards. Since then, I have completed level 2 NVQ in customer services, and awaiting my certificate. I have also gone back to college and completed the first 2 levels of person centred counselling, and currently on the third level. I have also done my food safety in catering where I got a level 2 Award, and are now able to volunteer my services and cater small and large functions. I hope you liked your lunch?

I really look forward to the opportunities that present themselves to me now, although I am still caring for my son I see myself as Sue first, my aspirations for the future, I would love to see a skills college set up for children with Autism in Lewisham. I would love to be involved with that in some way. To use counselling to help people who feel as desperate as I felt. To continue supporting and giving back to carers Lewisham as I feel I owe them so much. To keep learning, growing and developing and helping others along the way.

## ‘John’

My name is John and I have been married to my wife Linda for the past 30 years. We have two grown up children and one grandson. We have lived at various addresses in xxxxxxxxxx for most of our married lives.

Linda first became ill about 30 years ago with Ulcerative Colitis and then a blood disorder (ITP) where her anti-bodies attack her platelets. Without her medication she would not survive many months. Then 25 years ago she was diagnosed with secondary progressive MS.

### **Support for caring role pre Carers’ Centre involvement**

In the first few years of Linda's illnesses there was not much to do in the way of "a carer's role", other than to take Linda to Hospital for various appointments. There were sporadic episodes of Linda being admitted to Hospital because her blood count would fall low and she needed transfusions of platelets. I would then have to take time off work to look after the children.

About 10 years ago as the MS progressed and the impact of Linda's drug regime took its toll, Linda was no longer able to work and that began a period of real struggle. Initially the situation was manageable and the days when Linda needed help were infrequent but over time they became more frequent. Linda also because of depression went through a phase of not taking her medicines correctly. There were also outbursts of anger and frustration. These were not always handled well by me.

We had attended the MS Society Unit in xxxxxxxxxx but Linda did not like it there. She was fearful of the potential future ahead of her based on some of the people she met.

As Linda's MS progressed, her ability to help herself has decreased quite considerably, she has great difficulty in walking and is very weak on her left side. This was causing falls and injuries ranging from minor cuts to having to attend hospital.

We did contact Social Services and they came out and helped by getting some rails fitted around the house and arranging for us to have a lifting device to help me get Linda up when she falls.

I was struggling with keeping my job going and trying to ensure that Linda was safe enough to allow me to go out to work.

The pressure on me eventually led to my own health failing in that the stress of trying to manage a challenging job and cope with Linda's needs led to me ending up in the Cardiac Unit.

It was obvious that the situation could not continue and we decided that I should leave my job, taking what pension was available to me to enable me to look after Linda and hopefully find some sort of employment that would supplement our income.

In terms of support for me as a carer, I was not aware that such support existed nor can I remember any of the people we met with in terms of Doctors, Nurses or Social Workers ever suggesting that such support was available or even enquiring if I was alright or coping well.

### **Support for my caring Role from my local Carers’ Centre**

I first contacted my local Carers' Centre in October 2009, when I had got to the point of walking away from my caring role. We had had a very difficult 18 months from the time I left work to that point. The reasons being Linda's deteriorating health and the level of care that she now needed. Linda felt frustrated with the situation and this led to rows, we even went to Relate for counselling.

When I first contacted my local Carers' Centre, I spoke to a Carer Support Worker (CSW) and for the first time in many years, there was someone willing to listen to me rather than the offering usual retort was "but it is much worse for your wife because of her illness".

I had seen a poster for the Carers' Centre in my GP's Surgery.

Since making contact with my Carers' Centre, my life and my ability to provide the care needed by my wife has improved significantly.

I attend the monthly meeting held for carers in xxxxxxxx, we share experiences and feelings. We also get an update from the CSW about what is going on and we have guest speakers who deal with specific subjects.

I have attended various modules of the Caring with Confidence Courses, these have all enabled me to learn how to manage myself better and thereby improve my health and my ability to support Linda.

Through my Carers' Centre I have been given a one year subscription to a gym in xxxxxxxx, where I am able to improve my overall fitness and health. It also gives me sometime to myself, which helps reduce the stress and strain of caring.

With the support and encouragement of my Carers' Centre I have also become involved in lobbying my local MP about the support carers need and have arranged with the CSW for him to come to a meeting with local carers.

I have been introduced to organisations such as Crossroads where I can get help with someone to be with Linda if I need to go out for any length of time.

Without my Carers' Centre I seriously doubt if I would still be caring for my wife.

My Carers' Centre is the only organisation I have come across where the focus is on the well-being of the carer and you are not just a faceless person who supports a person in need of care.

## ‘Janet’

My name is Janet and I have a 20 year old daughter who has suffered with mental health problems since she was 14 when she was diagnosed with anorexia. She has been under the care of the CAMHS team as an adolescent and is now under the CMHT.

She has had various diagnoses but presently her diagnosis is of borderline personality disorder and she also has problems with drugs and alcohol. Her illness has been characterised by self harm, such as burning or cutting herself. She has made a number of suicide attempts, three of which were very serious and has been sectioned twice.

Between the ages of 16 and 18 she was in 6 different psychiatric units including an adult mental health ward when she was 16 and two locked wards one of which was an adult facility. When at home she would often run away and was arrested for possession of cannabis. Unknown to us she stopped going to school shortly before she took her first overdose.

Her mental health problems meant she had lots of rituals and found it difficult to go out and mix with people.

The drugs meant she could become physically and mentally abusive at home and resulted in her having a psychosis where she wanted to turn yellow and would eat only food she had dyed yellow.

It is impossible to describe the devastation felt by myself and her father. We felt guilty, ashamed, helpless and hopeless. I suffered a reactive depression and at one time felt that the pain was so unbearable that the only way out was to kill myself or my daughter. I gave up work so we could try and care for her at home and because there were so many crises and meetings to attend to.

This had a financial impact on us as did the extra costs of caring for and visiting our daughter in units up to two hours' drive away. We became isolated, it was difficult to talk to friends and family about what was going on in our lives. We could make no plans and could not be away from home together for fear of what might happen, we had become used to police and ambulances at our door and constant trips to A&E.

At the age of 18 my daughter went to a therapeutic community which she ran away from and ended up on the streets for 10 weeks before she asked to return home to live with us.

She is still at home and things are much improved, there has been no running away, no self harm, and she is not using illegal drugs.

At some point in all of this I contacted the local Carers' Centre. I cannot be sure now how I heard of them or why I contacted them I think it was for some advice but whatever the reason I am very glad I did. I was able to speak to an involvement worker who was very understanding, non judgmental and supportive. From then on the worker kept contact with me at first every two weeks and then every month. It was lovely to receive these calls and for someone to ask how I was and to focus on my well being. I was also able to talk through how I felt about what was going on. I made a difficult decision at some point that my daughter could not return home if she was using drugs or alcohol as I could not cope with her behaviour. The Carers' Centre provided me with an opportunity to talk this through without feeling I was being judged. They also pointed me towards some useful literature about my daughter's condition.

Once things had improved and were more stable at home I took up the opportunity to train as a carer trainer. I really enjoyed the training for that role and it helped to give me some confidence which in turn helped when I had to attend meetings about my daughter's care with professionals. In the past I had often felt angry and unable to be assertive and put my point across.



It was also lovely to meet with other carers and share experiences. This made me feel less alone and isolated. After completing the training I have been able to use it to help train professionals which has helped me gain in confidence and has increased my self esteem both of which had been battered by my experiences. I also felt worthwhile as I hope that I can help in a small way to improve services for others and it was nice to receive a small payment for my work which indicated it was valued.

I have also become a carers' representative and sit on a committee for the development of good mental health and suicide prevention and for the development of training in the fields of mental health and drugs and alcohol abuse. I feel proud to represent the views of other carers and again hope to improve services.

I have also been supported by an involvement worker to attend a conference of professionals and carers of those with a personality disorder diagnosis. I am very interested in this because of my daughter's diagnosis and I was able to stand up and put my point across to 80 people including representatives from the department of health. I am sure I could not have done this without the help and support from the Carers' Centre. As a result of my increasing confidence I am even able to contemplate a return to work.

The Carers' Centre have also given me support and information that led to my having a Carers Assessment so that care could be put in place so my husband and I could take a week's break this year together without my daughter. We hadn't been able to do this for over 4 years and it made a real difference to our well being.

Without help and support from the Carers' Centre I don't think I would be where I am today. I have survived what has happened to me and have come out better able to deal with my situation and the continuing difficulties with my daughter and my carers' role. I have increased confidence and feel less isolated. I feel I am involved in something worthwhile in helping to educate professionals about carers and what they need and how to improve services for carers and their loved ones.

## ‘J’

J was 16 years old when the YCFP started to work with her. She was experiencing difficulty at school. She was about to sit her GCSEs and the school had failed to acknowledge that her caring responsibilities had played a major part in her lack of school attendance and low level of academic achievement. She is a very bright young woman and the school were very frustrated as she felt that she was capable of achieving a very high standard at school. There was a lot of anger being exchanged between the family and the school.

J has been caring for her mother who has complex mental health issues, and who is also physically disabled. She also cares for her younger brother who is on the autistic spectrum and the two siblings witnessed domestic violence towards their mother from her father during her early years.

YCFP assessed the needs of the family as complex and began to try to unpick the many layers to the family's history. J had been administering claims for benefits, housing appeals and appeals for her brother to be statemented so that he could have his needs met both in and out of school without support and at this stage she was a very angry and frustrated child. We started to acknowledge the extent of her caring role with her and discovered that she is enormously proud of her caring role. We worked with this sense of pride and we acknowledged how much anger she and the whole family were feeling towards other professionals who have been involved in the past. And we focused on building a trust between the family and the YCFP. We also encouraged the family to think about beginning to trust other professionals again with our support and co ordination. Talks were held with key members of staff at the school and the school agreed to concentrate their efforts on the subjects that they felt J could get by in. Together with J we then researched into home learning schemes that have a facility for students to learn on line at their own pace. We were able to source and secure funding for J to study and sit her GCSE'S and two AS level subjects which she is now studying from home. She finished school in July 2010 with four GCSE'S feeling much more empowered and relaxed. We continue to work with the family on other more long term and complex issues.

## ‘John’

John is a twelve year old boy who cares for his mum and 3 younger sibling's ages 7, 5 & 4. The referral came for John's school due to concerns about his caring responsibilities. John did the shopping, cooking, washing dishes, preparing and getting both his siblings and himself to school. He became exhausted, angry, miserable and sad. He had poor school attendance and attainment, whenever he made it to school; he was persistently late, tired and lack concentration and attention at school.

Mum is a single mother suffers with depression and anxiety due to the death of her disabled brother and separation from her husband. Mum dealt with her depression by shutting down and could not maintain daily routines for the children. i.e. cooking, cleaning, school run etc In addition, mum did not respond to letters and was at risk of losing her home due to rent arrears, housing benefit claim not renewed and failure to attend medical assessment for Employment Support Allowance (ESA).

The Young Carers Family Support worker (YCFS) visited mum at home, she engaged with the service promptly and exclaimed that she has longed for this type of support for a long time. YCFS called a family conference and identified the support network for mum. Dad is now supporting with school runs and has the children to stay over with him 2 days a week. Nan supports with shopping until mum is able to take up the tasks. The YCFS contacted the Housing Association to explain the family circumstances and supported mum to apply for ESA and housing benefit. The application for ESA was successful and HB/CT benefit was back dated to pay off the arrears.

John's now attends drop-in twice a week at Carers Lewisham; he participated in the October half term holiday activities and has been on a residential weekend. The school have noticed positive changes in John's self-confidence, improved attendance, academic achievements and social skills.

Mum described the support from the Young Carers Family Support as her lifeline and without it her children would have suffered neglect and lack emotional warmth and love.

## Carer 'X'

### **Who**

Carer X is in her 40s and hails from the council estates of the north-east of England. During her childhood, the area was considered to be an area of high social deprivation. Whilst the council estate where she lived had originally been well kept and populated with hard working, good hearted tenants, gradually the estate became neglected and tenants with anti-social behaviour moved into the neighbourhood.

In this environment and when aged 11, Carer X was left home alone with a Mother who had a huge breakdown that lasted many years. This was characterised by her Mother – Mrs X – being extremely withdrawn, perpetually in bed and indulging in severe self-neglect. She was also very angry and would, many times on a daily basis, graphically describe how she would commit suicide.

Carer X, being a child, thought that this was part and parcel of life; she and her Mother did not realise that Depression is an illness that requires treatment. And in those days, mental health issues were something to be hidden away; there was a stigma about it (and still is). As people prefer not to be in the company of those suffering from Depression, Carer X and her Mother were shunned by family, friends and society. No one wanted to know them. Thus Carer X was left alone to cope with a Mother who was very poorly and was unable to work, so they existed on miniscule Social Security payments. Carer X did all household chores such as washing, ironing, cleaning, gardening, paying bills and food shopping (although frequently there was not enough money to buy even the basics). She would also try to persuade her Mother to bathe but, most of the time, these requests would be ignored.

### **Why**

Depression is about loss. Whilst the reasons for Mrs X's breakdown are complex, a number of factors coincided to induce the breakdown, namely: Divorce; poverty; the empty nest (her sons had left home); and the menopause. But the biggest factor was the death of Mrs X's Mother in childhood. The death of a mother in childhood – or the physical or psychological displacement of the mother - is known to be the biggest cause of mental health issues. The loss and grief that she had experienced as a child had never been addressed and, thus, this was a key factor in Mrs X's breakdown and bouts of severe Depression since.

### **What**

For the following 30+ years, Mrs X has continued to experience severe Depression. It was a vicious circle: The area of social deprivation that she lived in, coupled with living on the breadline exacerbated the depression. This made it harder for Mrs X to cope with life so the isolation and self-neglect continued. It was a very difficult situation for Carer X but, given that everyone had deserted her Mother, she felt a very strong sense of responsibility for Mrs X, trying in every way possible to improve the situation.

However, Carer X – due to low self-esteem and lack of local opportunities – gravitated towards low paid jobs so was not in a strong financial position to help her Mother escape the estate where she lived.

### **Where / when**

For the past 14 years, Carer X has lived in Westminster but continued to provide care to her Mother, based in the north east of England, who is ageing and becoming increasingly frail. Realising that she required increasing flexibility as to how and when she worked, Carer X became self-employed and, because of the situation with her Mother, had installed Broadband into her Mother's home so that she could work there, as well as at her home in London.

Carer X was travelling up to the north-east of England once a month, then every 3 weeks, then every 10 days, as Mrs X's condition deteriorated. However, coping with a Mother who was struggling with life and still indulging in

severe self-neglect over 30+ years took its toll on Carer X physically, psychologically and financially. Like an egg shell starting to crack, she realised that she could not cope any more with the situation and screeched to her family for help, even saying that she was suicidal. But, shamefully, no one came to her aid.

At this point, Carer X had experienced three car crashes within one year, the last one being so horrific that it deterred her from driving again. After this car crash, she resolved to 'kidnap' her Mother and bring her to live temporarily at her home in Westminster to buy Carer X time, so that she could look into options for ongoing care.

Eventually Carer X sought help from her GP who referred her onto counselling within the GPs practice but, after the rationed sessions had been delivered and it was clear that more help was required, Carer X was referred as an Outpatient to a local psychiatric hospital. At the time, it felt that it was only the Clinical Psychologists there – who are paid to help - who cared if Carer X was alive or dead.

And during all this time – when feeling very, very fragile – Carer X continued to provide care.

Needless to say that her work suffered too.

### ***Carers Network Westminster***

Feeling desperately low, Carer X stumbled across the Carers Network Westminster (CNW) and contacted them. A representative from the CNW called at Carer X's home and mentioned the help that they could provide. For example, the CNW had a Holiday Fund and she suggested that Carer X submit an application. Bearing in mind that, having delivered care for 30+ years, Carer X had received not one penny from the public purse, the thought of receiving a holiday was uplifting. At the end of the session Carer X cried because no one had ever taken an interest in her well being as a Carer.

Since that time, Carer X has:

- ▶ Received a holiday for herself. Given that, over a 30+ year period, it has cost Carer X vast sums of money - that she could ill afford - to provide care, then sanctioning a holiday, particularly when she was under so much stress, was much appreciated.
- ▶ Attended a 6 week session about caring for people with mental health issues. The carers on the course became such good friends that Carer X created First Monday, a support group for carers of people with mental health issues.
- ▶ Became involved with the CNW's Carers Action Steering Group, a committee that provides input in carer strategy for the CNW.
- ▶ Delivered a communications' workshop for carers, to encourage them to stand up and speak about them and their experiences.

Listening to other people's stories has been humbling, moving but inspiring for Carer X. Prior to becoming involved with the CNW and the carers that are involved with the organisation, Carer X felt that her existence as a carer was so strange; that she was on the periphery of society exacerbating her feelings of isolation. Also, since childhood, she had been ashamed of her family life, hiding it away from others. However, since becoming involved with the CNW and other carers, she has learned to be proud of being a carer, and to proclaim to others the superb values that carers bring to society: Caring for those that society would prefer to forget about; absolute resilience; and innate goodness.

Further, the staff of the CNW – many of whom provide care themselves – have been a source of goodness. All staff are intelligent, highly professional and utterly carer-focused. After years of delivering care alone, without a support structure, Carer X is comforted to know that she has the support of CNW staff and other carers too.



Carer X's world is much better because the CNW is in it. A huge, heartfelt thank you to everyone.

## F. Sensitivity Analysis

Various assumptions have been made in the course of preparing this analysis and the detailed tables of calculations in Appendices B and C. Some relate to estimates made by the Action Research group in coming to the views of outcomes, and some relate to the interpretation of information arising from other research work and statistical analyses referenced in this work.

In order to assess the extent to which these assumptions are material, potentially key assumptions have been identified. Each has been subjected to variation within what appears to be a reasonable range, and the effect on the total evaluated outcomes under the study has been recast.

In the context of the research available for carer outcomes, the proportions of carers likely to experience certain outcomes are felt by the Action Research group to be consistent with observed data. The key assumption is therefore the proportionate deduction made for those carers for whom support helps to manage but does not alleviate the outcomes measured. The models in Appendices B and C include a deduction of 50% to account for this. The impact of a 50% increase in this deduction (i.e. increase the deduction to 75%) is shown below as sensitivity one.

We have also prepared a sensitivity analysis to consider the impact of different levels of attribution to other agencies. The models in Appendix C include a deduction of 50% for alternative attribution. The impact of a 50% increase in this deduction (i.e. increasing it to 75%) is shown below as sensitivity two.

Sensitivity three shows the impact of combining sensitivities one and two.

Sensitivities four and five show the impact of increasing or decreasing the proportion of gains recognised in the year of registration with a Carers' Centre by 10%.

The impact of variations in these key assumptions by reference to the total evaluated outcomes is shown below:



Summary evaluation	Total evaluated outcomes (£'000)	Difference compared to Appendix C (£'000)
Evaluated outcomes per Appendices B and C	72,982	
<b>Sensitivity 1</b>		
Increase deduction to 75% for carers for whom an outcome is not alleviated	36,563	(36,419)
<b>Sensitivity 2</b>		
Increase alternative attribution to 75%	27,458	(45,524)
<b>Sensitivity 3</b>		
Combination of sensitivity 1 and sensitivity 2	13,801	(59,181)
<b>Sensitivity 4</b>		
Proportion of gain in year 1 increased to 70%	71,710	(1,272)
<b>Sensitivity 5</b>		
Proportion of gain in year 1 decreased to 50%	74,253	1,272

Of the two sensitised assumptions shown above, the models are marginally more sensitive to changes in alternative attribution. The model is least sensitive to a change in the proportion of gains recognised in the year of registration or later years.

The results of the sensitivity analysis shown above highlight that either or both of sensitivity one and two might occur without altering the conclusion that the outcomes of the work done by Carers' Centres significantly outweigh the costs to achieve them. Under the harshest scenario (sensitivity three) the evaluated outcomes of £14 million per annum would be at least £9 million greater than the annual funding for the five centres.

It must, however, be noted that the evaluation excludes areas of gain, notably improved personal satisfaction and social inclusion of carers and the people they care for, the value of skills development among carers and the brand value of Carers' Centres. In these areas, gain is achieved but no figures have been attributed to them in this report.

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