A Stitch in Time?

Carer organisations Case Study:
Explaining and evaluating their contribution

coalition
of carers in Scotland

University of
Strathclyde
Glasgow

e**s** **Evaluation**
Support
Scotland

j**i**t **joint** improvement team
creativity, collaboration and continuous improvement

The Scottish
Government

Introduction

Background

In the Stitch in Time? programme we identify the role of the third sector in Reshaping Care for Older People (RCOP).

In addition to an overall model, we are using a range of case studies to showcase particular interventions or types of project.

It is challenging for carers organisations to evidence their impact because so much of the work that they do is preventative.

The Stitch in Time? programme team worked with a range of carers organisations in Scotland to develop a model to identify their role in supporting organisations who care for people of diverse ages.

In this case study we worked with eleven carers organisations, with diverse models of provision, to capture and further develop their evaluation approach.

For a fuller report including an account of the project development, examples of the information being collected, the tools used, how data is stored and aggregated, and sample logic models, go to Evaluation Support Scotland's website.

Go to **www.evaluationsupportscotland.org.uk** for "A Model to explain the third sector contribution to Reshaping Care for Older People"

Carers organisations provide a universal service and play a vital role in supporting unpaid carers who in turn support relatives and friends with diverse care needs. Much of the work of carers organisations is preventative, in sustaining carers through challenging caring situations, and in avoiding crises. The types of support provided varies, but can include:

- Emotional support and counselling

- Training and learning opportunities

- Financial planning and welfare rights

- Peer support

- Advocacy

- Information and signposting

- Provision of short breaks

The organisations involved represent diverse geographical locations, from urban to island communities. They also work with diverse caring situations and include two mental health carer projects. One project provides carer support training to NHS professionals in Lothian.

Participants included the following individuals: Falkirk Carers Centre; Voluntary Services Agency (VSA) Aberdeen/Aberdeenshire; Inverclyde Carers Centre; VOCAL project working with professionals; Glasgow Association for Mental Health (GAMH); Support in Mind; East Lothian Carers Centre; Shetland Carers Centre; West Lothian Carers Centre, and East Renfrewshire Carers Centre.

The current situation

There are a estimated 650,000 unpaid carers in Scotland. 1 in 8 of the Scottish population who are involved in providing care and support to a family member, friend or neighbour to enable that person to continue to live in the community[1]. There are also many 'hidden carers' who do not receive support from services. Although the health and social care system depends on unpaid carers, they often experience heavy emotional and physical demands. The role of carers organisations in providing a universal service and one stop shop can be critical to sustaining the caring role, and to the sustainability of statutory services.

The Coalition of Carers in Scotland (COCIS) exists to advance the voice of carers by facilitating carer engagement and bringing carers and local carer organisations together with decision makers at a national and local level. COCIS connects with carers and carer organisations from the Borders to the Shetland Isles through working with members identified the following needs:

• Support to assist member organisations in establishing an outcomes approach to the monitoring and evaluation of services

• Support for members to produce evidence on the value of projects funded through Carer Information Strategy (CIS) Monies and the Reshaping Care for Older People (RCOP) Change Fund

• Establishment of a national picture of the outcomes achieved locally through CIS and Change Fund funded projects. Colleagues in health, local authorities and government consistently emphasise the need for evidence to support investment in preventative services, such as carer support

The project

A key concern for the organisations involved in this project has been to develop means of evidencing the preventative nature and value of the work they do to support carers. Logic modeling can provide a framework to help structure this type of evaluation. At the same time, many carers organisations are embedding outcome-based planning with carers, which can also help with evidencing preventative work.

This project comprised:

• The development of a carer specific logic model, which can be used as a tool for carer support organisations to develop their own model to evaluate outcomes

• Training for carers organisations to develop their own logic models and to consider how to gather evidence about their outcomes

• Ongoing support to carers organisations to complete their logic models and to use these as the basis for evidence of the benefits of preventative support and the outcomes for carers, and provide a report on the work

• The development of a short summary of the most important evidence and examples of self-evaluation evidence

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1   http://www.scotland.gov.uk/Topics/Health/Support-Social-Care/Unpaid-Carers

Our model of provision

Developing a common approach to evaluation

We developed a carer specific logic model which can be used as a tool for carer support organisations to develop their own model to evaluate outcomes.

The model on page 5 shows what we do and the difference we make. In brief:

A growing percentage of the population provide substantial care to family and friends who need support to remain in the community. Carers organisations in turn support many of these carers, sustaining them in their role. Some also train staff in other sectors to be more carer aware, enabling further carer support.

There is a broad range of **inputs**, including: unpaid carers; cared for person; family/friends/neighbours; local community; local authority services/NHS services; third sector services including carer organisations; independent sector services; physical resources; staff/ volunteers; premises, and funding.

Our key **areas of activity** include: emotional support and counselling; training and learning opportunities; financial planning and welfare rights; peer support; advocacy; information and signposting, and provision of short breaks

We have **outcomes** for our service, the cared for person and professionals. However, our ultimate aim is to bring about better outcomes for carers. This, in turn, allows carers to care for longer, achieve their own outcomes and adjust to life after their caring role ends.
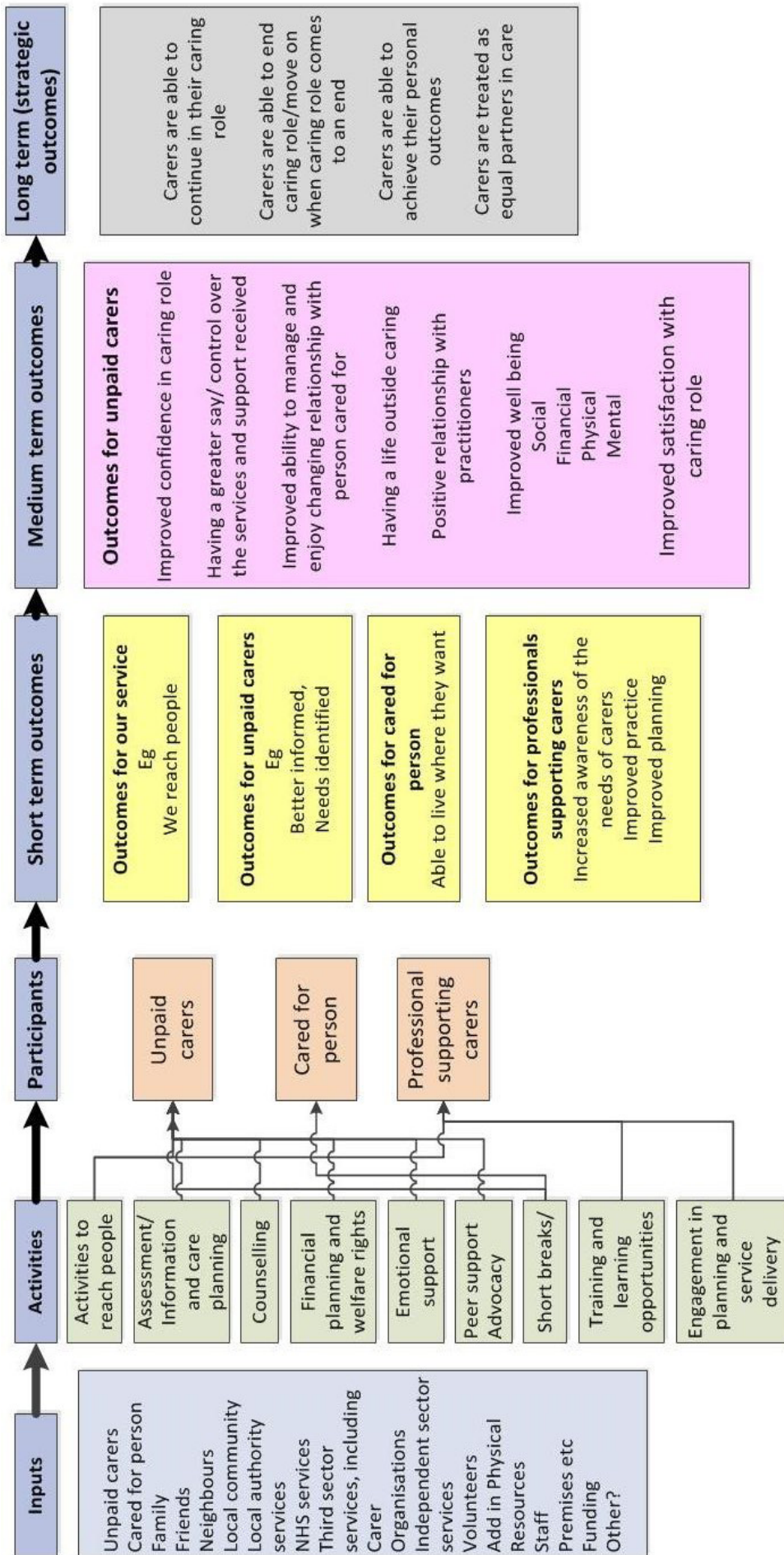
For a tailored logic model developed by Inverclyde Carers Centre go to page 6.

Prior to this project, many of the organisations had already developed approaches to evaluation, including identification of outcomes. All eleven organisations involved attended at least one workshop, with most attending both. Most reported that the workshop on logic models provided a framework enabling them to link inputs, activities, outputs and outcomes, which could help to identify the preventative value of their work. Feedback during follow up contact and at the second workshop identified key themes on the experience of developing the models:

- Attending the workshop generated real enthusiasm for the approach. However, while some organisations felt able to go ahead and develop a model, others felt a bit overwhelmed by other pressures and found it more challenging.

- Developing a model was described as a messy process; it was importance to view the model as something which could be reviewed and refined over time

- It was best to avoid getting too bogged down in detail, instead identifying key outcomes and describing activities in broad terms.

- The process of development was viewed as important as the model itself because "It makes you think deeply about what you're doing, how and why."

- It possible to have an organisational model, and more detailed 'nested models', linking to organisational outcomes, with additional outcomes along the way.

- Models which were bottom up rather than top down were preferred, ensuring that the focus remains on personal outcomes for carers (and for staff)

Carers organisations' model of provision

Inputs

Unpaid carers
Cared for person
Family
Friends
Neighbours
Local community
Local authority services
NHS services
Third sector services, including
Carer Organisations
Independent sector services
Volunteers
Add in Physical Resources
Staff
Premises etc
Funding
Other?

Activities

Activities to reach people

Assessment/ Information and care planning

Counselling

Financial planning and welfare rights

Emotional support

Peer support Advocacy

Short breaks/

Training and learning opportunities

Engagement in planning and service delivery

Participants

Unpaid carers

Cared for person

Professional supporting carers

Short term outcomes

Outcomes for our service
Eg
We reach people

Outcomes for unpaid carers
Eg
Better informed,
Needs identified

Outcomes for cared for person
Able to live where they want

Outcomes for professionals supporting carers
Increased awareness of the needs of carers
Improved practice
Improved planning

Medium term outcomes

Outcomes for unpaid carers

Improved confidence in caring role

Having a greater say/ control over the services and support received

Improved ability to manage and enjoy changing relationship with person cared for

Having a life outside caring

Positive relationship with practitioners

Improved well being
Social
Financial
Physical
Mental

Improved satisfaction with caring role

Long term (strategic outcomes)

Carers are able to continue in their caring role

Carers are able to end caring role/move on when caring role comes to an end

Carers are able to achieve their personal outcomes
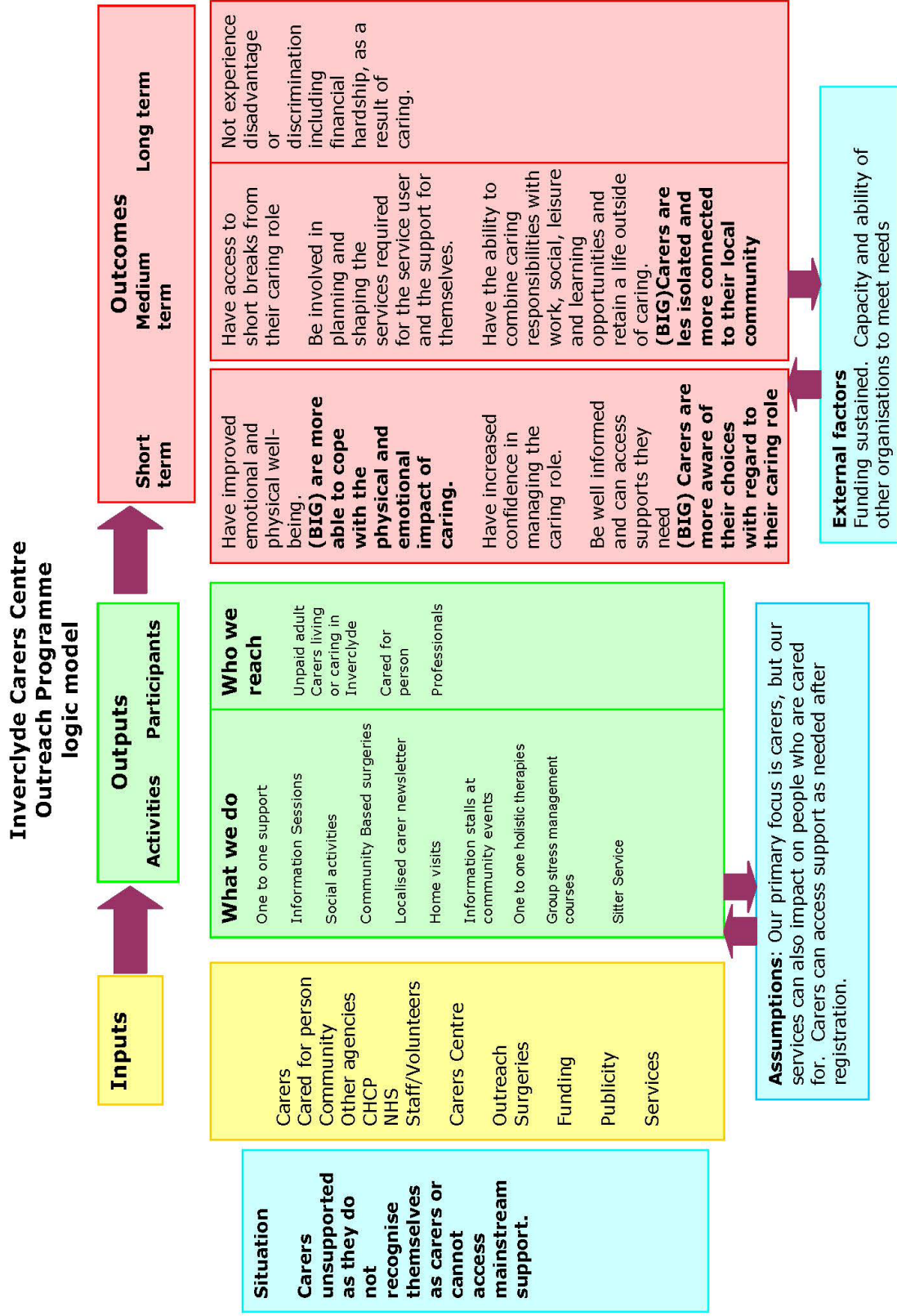
Carers are treated as equal partners in care

Assumptions
Our primary focus is carers, but our services can also impact on people who are cared for
We are person centred, we find out what's important to carers through conversations

External factors (which may affect outcomes)
Availability of local services, supports and opportunities
The person cared for becomes more ill/ has greater needs

Inververclyde Carers Centre's nested model

Inverclyde carers centre have developed a series of nested logic models. They have one logic model for the organisation as a whole, and then more targeted logic models for specific projects. The example below is the model for their outreach project. The manager is clear that the logic models represent theories of change, and that they are works in progress. They expect that they will adapt their logic models as they gather more evidence and develop increasing understanding about their activities and outcomes.

Inverclyde Carers Centre Outreach Programme logic model

Inputs

Situation

Carers unsupported as they do not recognise themselves as carers or cannot access mainstream support.

Carers
Cared for person
Community
Other agencies
CHCP
NHS
Staff/Volunteers

Carers Centre

Outreach
Surgeries

Funding

Publicity

Services

Outputs

Activities   Participants

What we do

One to one support

Information Sessions

Social activities

Community Based surgeries

Localised carer newsletter

Home visits

Information stalls at community events

One to one holistic therapies

Group stress management courses

Sitter Service

Who we reach

Unpaid adult Carers living or caring in Inverclyde

Cared for person

Professionals

Outcomes

Short term

Have improved emotional and physical well-being.

(BIG) are more able to cope with the physical and emotional impact of caring.

Have increased confidence in managing the caring role.

Be well informed and can access supports they need

(BIG) Carers are more aware of their choices with regard to their caring role

Medium term

Have access to short breaks from their caring role

Be involved in planning and shaping the services required for the service user and the support for themselves.

Have the ability to combine caring responsibilities with work, social, leisure and learning opportunities and retain a life outside of caring.

(BIG)Carers are les isolated and more connected to their local community

Long term

Not experience disadvantage or discrimination including financial hardship, as a result of caring.

External factors
Funding sustained.   Capacity and ability of other organisations to meet needs

Assumptions: Our primary focus is carers, but our services can also impact on people who are cared for.   Carers can access support as needed after registration.

Based on www.uwex.edu/ces/pdande/

Evaluation approach and challenges

Go to **www.evaluationsupportscotland.org.uk** for "A good outcome: Evidencing how local carer organisations are supporting carers to achieve their personal outcomes"

Carers organisations gather feedback from carers through:

- Surveys and questionnaires

- Focus groups with carers

- Individual communications from carers including letters

- Monthly case studies by staff

- Contact sheets

- Videos and photographs

In the next few pages we showcase methods developed by carers organisations. While it was agreed that flexibility was required because of the diversity of organisations involved, core common challenges were identified with evaluation.

- The core evaluation challenge for carers organisations is being able to demonstrate the value of the preventative work that they do, as it is always difficult to prove that crises have been avoided

- Carers organisations also work with large numbers of people, many of whom seek support on a one-off or episodic basis, and it is more difficult to capture transient as compared to planned and regular interactions

"Evidencing outcomes is a sticking point, especially when it comes to soft outcomes. We run a six week stress management course. A carer might feel better but how do we show that. It's all very well doing evaluation sheets but they can be very statistical... How do we show our impact?"

- As the nature of support is informal and conversational,

formal methods for collecting evidence have to be carefully managed

- *"It is important that the relationship is not disrupted by measurement. We want our staff to understand the conversation as an intervention in itself."*

- While the validation and support provided by carers organisations can be critical many do not see themselves as carers until they are in crisis

- The logistics involved in remote communities bring additional challenges. Dispersed communities make provision of one to one and group support more challenging

- Carers organisations are subject to diverse evaluation demands from different funders who may demand very different forms of evidence. The multiplicity of reporting frameworks was a particular concern:

"My biggest anxiety around this work is the setting of different outcomes by different organisations. The [local] Carers Strategy includes outcomes and outputs... There are also Change Fund projects where outcomes may vary from the Carers Strategy... Then there were the outcomes from COCIS. Although they don't quite fit each other, I am keen to stick with the COCIS logic model as far as possible." **(Carer centre manager)**

What follows in the next few pages are examples of different evaluation methods used by carers organisations.

Examples of evaluation methods

Inverclyde Carers Centre's monthly case study

Inverclyde introduced monthly case studies in the last year, as a way of sharing good practice examples and to support staff towards being able to identify outcomes which can now link to the logic model shown in page 6.

Example Monthly Case Study Number 1

Carer Support Worker:
Subject: **Outreach Respite and Benefits**
Outcome: **Carer having "me time" and Benefit advice to reduce concerns about making ends meet**
Date: **9th and 25th September 2014**

Carer referred by Reablement team, stays with and cares for his mother who is frail and elderly and is living with Parkinsons. Carer has very little time to himself and although he has some help from his sister bears the brunt of the caring role himself. He wanted to make sure his income was maximized as he is struggling to manage the family finances.

In the first visit, passed on leaflets and Carers Self Assessment, spoke at length about Long Term Planning, Outreach respite and a benefit check with particular emphasis on Carers allowance for himself.

After the first visit, a financial Fitness appointment was set up, Carers allowance form processed, awaiting outcome. Cared for assessment set up with xxx services manager, at the family home on Tuesday 23rd September. Respite commenced 25th September, support worker assigned cared for person.

The carer came back in on 29th September to drop off his self-assessement. He said he hadn't realised how stressed out he was until he had a **chance to talk things through** in his first visit and now that he was **feeling calmer and much more hopeful**, was also keen to **engage within his community at a poetry class** every Thursday night, 7pm – 10pm. He said that **he now knows where to come** if he got stressed again. Carer very appreciative of support, review of respite in one month's time.

(NB Personal identifiers have been changed)

Falkirk Carers Centre's electronic carer support plan

FALKIRK Carers Centre have recently moved towards an outcomes approach and have adapted their IT system to be able to collect outcomes data. At this stage they are already able to collate statistics about outcomes, and their systems and tools also allow them to collect comments, quotes and individual feedback from carers in relation to all of their carer support activities. Work is continuing to support the shift from needs led to outcomes focused recording by staff. Falkirk Carers Centre provided a snapshot of a carer support plan from their database.

Carer Support Plan — Mrs M Test

Indiv Ref: 7673
CSP Ref: 1

Assessment Summary

	Assessment	Outcomes Review
1. Health and Wellbeing	Very Important Issue	Big Improvement
2. Confidence in Caring	Important Issue	Small Improvement
3. Life Outside Caring	Very Important Issue	Big Improvement
4. Economic Wellbeing	Small Issue	Big Improvement
5. Involvement	Not an Issue	Not An Issue
6. Relationships	Not an Issue	Not An Issue
7. Other Issues	Not Discussed	Not Discussed

CSW Initials	SC
CSP Start Date:	14/02/2013
CSP to Carer Date:	15/02/2013
CSP Completed Date:	14/02/2013
Outcomes Review Start Date:	03/03/2013

Issues Identified	Actions Agreed	By Whom	When	Date Completed
Mary would like help to apply for Attendance Allowance for her husband	Make referral to DWP Home Visiting Service	SC	14/02/13	14/02/13
Mary feels very stressed as a result of her caring role	Give Dealing with Stress Booklet	SC	14/02/13	14/02/13
	Apply for Creative Breaks grant for short break for Mary	SC/MS	21/02/13	21/02/13
	Attend Care with Confidence Session - Coping with Stress	MS	24/02/13	24/03/13
Mary has no time to pursue her own interests	Contact Social Work to request Community Care Assessment for Mr S and discuss respite.	MS	By end February 2013	27/02/13
	Speak to family and arrange cover for Wednesday mornings to enable carer to come to weekly drop in	MS	By end of February 2013	20/02/13

Carer Support Plan Assessment Start Date	14/02/2013	Carer Support Worker's Name:	Sharon Campbell
Carer Support Plan Review Start Date	03/03/2013	Date Carer Support Plan to Carer:	15/02/2013
Carer Support Plan Completed Date	14/02/2013		

Shetland Carers Centre's focus group report

Shetland Carers Centre hosted in Belmont House, Unst, Sheltand, their first ever `Come Along by`, probably the most northerly carers residential.   The idea behind their event was first and foremost to have an event that catered for carers in the north isles of Shetland, as feedback they gathered recently had shown how difficult, costly and lengthy it can be for carers to travel to Lerwick to attend meetings or events. It was also hoped that the event would be of an informal nature offering a mix of information sessions, focus groups and social interaction. The accommodation was open for those wishing to stay overnight but could be flexible to accommodate for care needs and allow carers to dip in and out of sessions as necessary.

Belmont House `Come along by` Carers residential

On a dark cold Tuesday morning in December we opened the lovely wooden doors of Belmont House, Unst, Shetland to our first ever `Come Along by` probably the most northerly carers residential!

 The idea behind our event was first and foremost to have an event that catered for carers in the north isles of Shetland as feedback gathered recently had shown us how difficult, costly and lengthy it can be for carers to travel to Lerwick to attend meetings or events. It was also hoped that the event would be of an informal nature offering a mix of information sessions, focus groups and social interaction. The accommodation was open for those wishing to stay overnight but could be flexible to accommodate for care needs and allow carers to dip in and out of sessions as necessary.

The event opened with an introduction about the event, sessions and venue given by Jo McPherson and Karen Hannay, Carer Support. A Focus group then followed lead by Stephen Plunkett, Health and Social Care alliance and Jo McPherson, Carers Support Worker. This was an informal group discussion on using the Virtual Carers Centre for information gathering. We wanted to evaluate the first stage of the VCC project so worked with the Alliance to develop topics on had we been successful or did we miss things? This was followed by a discussion on the best way to progress ideas for stage two looking at IT support training, lap top and tablets for carers, Skype support sessions and other possible developments. The event was very helpful with points being put forward by carers covering;

- How useful it was to have one place where carers can access local support information.

- Most carers were using it to find out about their next group meeting date and time.

- Links could be incorporated to the local authority short breaks (Laburnum) newsletter etc as some found it easier to navigate the VCC than the wider local authority website.

- The development of a carer forum was discussed where private log in passwords could be issued to carers wishing to join the group. Carers could leave questions or topics they would like covered and an admin staff member could then leave further information or attend for interactive discussion.

- The problem of the lack of Full Island wide broadband was mentioned. This is something to bear in mind when setting up the forum to ensure people can join in.

- The idea of Skype, Google party virtual support was popular but people felt it must go hand in hand with meeting people in person so that a relationship could be established probably prior to the virtual group link ups taking place.

- The idea was put forward that we work together to develop a virtual tour round the new Independent Living Centre in Lerwick showing carers what the centre has to offer. The video recording could then be added to the Virtual Carers Centre so that people from outside Lerwick can plan a successful visit. (This is now in the process of being made)

The next session was an Information sharing session on Telehealth by Clint Sentence (Tele Health Manager) a very useful informative session with many carers expressing interest in the aids being demonstrated by Clint. A development suggested by two carers of children with Autism was to use the virtual carers centre to set up an App forum where new and existing apps could be tested out by carers and feedback on usefulness given on the site which could then help other carers considering using apps. (Funding for this service development is now being sought.)

Other sessions covered a Short breaks and respite options discussion group and a short presentation on a new parent+ group due to start both in the Isles and in Lerwick. A presentation was given on a recent VAS scoping project from JoAnne Connors and Jo McPherson.

VOCAL Carers Centre recorded carer outcomes

VOCAL carers centre was an early implementer of an outcomes approach in Scotland. They have invested efforts in supporting staff to record outcomes in the database. The following example is an extracts from the baseline and reviews for different carers. This example has been anonymised.

Example:

Baseline: outcome - improved confidence in managing their caring role, identified by the carer as a 'very important' issue.

The carer is concerned about planning ahead and getting longer term arrangements in place for her husband, who has dementia, as her own health is not good. She wants to identify support for her husband in the event she should pass away.

Review: Big improvement

Carer now feels more confident for the future as they have put plans in place, both legal and financial. This includes having Power of Attorney in place both for herself and her husband.

Falkirk Carers Centre's group activities evaluation form

As part of their move towards an outcomes approach Falkirk have also developed evaluation forms which capture outcomes. An extract from the form is included here.

1. **Health and Wellbeing**
   (for example, you feel less stressed, less anxious, less isolated, your physical health has benefitted)

Big Improvement	Small Improvement	No Improvement	Worse

Please comment:

2. **Confidence in Caring**
   (for example, you feel better informed, better supported, more confident about caring, more able to cope)

Big Improvement	Small Improvement	No Improvement	Worse

Please comment:

3. **Life Outside Caring**
   (for example, you met some new people, made some new friends, learned a new skill, feel better informed about future possibilities for breaks or activities, feel more able to have a life outside your caring role)

Big Improvement	Small Improvement	No Improvement	Worse

Please comment:

A Stitch in Time?

A Stitch in Time? is a partnership project to support the third sector to collect and present evidence about its contribution to Reshaping Care for Older People (RCOP). The programme runs from April 2013 to March 2015 and focuses on third sector organisations working with older people and carers in Lothian.

A Stitch in Time? publications

A model to explain the third sector contribution to Reshaping Care for Older People

Focus on third sector interventions that allow older people to stay positive and in control

Indicator Bank for third sector outcomes for older people

Focus on third sector interventions to enable older people to keep or be more financially and materially secure

Focus on third sector interventions that make the physical and social environment more age friendly

Focus on third sector interventions that make the system work better for older people

Focus on third sector interventions to enable older people to keep or be more socially connected

Focus on third sector interventions that ensure healthy and active ageing

To accompany this series there are **evaluation case studies** and a number of **evidence reviews**.
To see all publications associated with A Stitch in Time please see Evaluation Support Scotland website.

Evaluation Support Scotland (ESS) works with third sector organisations and funders so that they can measure and report on their impact.

Evaluation Support Scotland

Supported by:

The Scottish Government