WHAT'S BEST FOR DUNDEE CARERS?

REPORT ON CARERS (SCOTLAND) ACT 2016 IMPLEMENTATION PILOT PROJECT IN DUNDEE

Dundee Carers Centre
Because We Care

Dundee
Health & Social Care
Partnership

ACKNOWLEDGEMENTS AND THANKS

- This report was prepared on behalf of the Project Implementation Group by Graeme Reekie of Wren and Greyhound Limited. Graham Reekie was employed as the Group's independent Chair and provided invaluable support and guidance during the Project.

- The excellent work completed by The National Carer Organisations, including the Coalition of Carers In Scotland provided a basis for the Eligibility Framework. The Dundee Carers Partnership would have not have been able to progress the draft local Eligibility Framework which was discussed in the project.

- Don Williamson of Shared Care (Scotland) provided an informative session to the Project Group about Short Breaks which was central to deciding and defining the information which was gathered around Short Breaks.

- The carers and Dundee citizens who were involved in all levels of the Project need to be recognised as inspirational and thanked for sharing their views, their time and their patience.

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CONTENTS

INTRODUCTION

The Carers (Scotland) Act (2016) introduces new rights for unpaid carers and new duties for local councils and the NHS to provide support to carers. It also introduces a number of new provisions to identify and support carers[1].

Before the Act comes into force on 1 April 2018, DHSCP wanted to explore how the Act could best be implemented to support carers to achieve their outcomes. A pilot project, funded by Scottish Government, took place between May and October 2017.

Dundee Carers Partnership set up an Implementation Group who co-designed and delivered the Project.

What's Best for Dundee Carers? Implementation Group

Lucinda Godfrey: Dundee Carers Centre

Joyce Barclay: Dundee Health & Social Care Partnership

Megan Clark: Dundee Carers Centre

Sarah Boath: Dundee Carers Centre

Ian Boyle: Dundee Carers Centre

Patrick Claydon: Dundee Carers Centre

Cathy Hamilton: Carer/Cairn Fowk

Sandra Marshall: Carer/Cairn Fowk

Donna Williamson: Dundee Health & Social Care Partnership

Michelle Young: Equally Well, Dundee City Council

Emma Wilson: Penumbra

Colin Campbell: Carer

Susan Johnston: NHS Tayside

Graeme Reekie of Wren and Greyhound Limited was the Independent Chair of the Group.

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[1] By carer we mean individuals who are providing, or plan to provide, care and support to one or more adult or child affected by illness, disability, frailty, mental health or alcohol or drug use.

KEY MESSAGES

The Project tested four provisions of the Carers (Scotland) Act 2016:

Section 6-9	Duty to prepare Adult Carer Support Plan (ACSP) including content required in ACSP
Section 21	Duty to set local eligibility criteria
Section 24	Duty to provide support
Section 35	Short Breaks Services Statements (SBSS)

The project generated learning about each of these provisions, resulting in a number of key messages as follows.

Duty to prepare Adult Carer Support Plan

Informal assessment and planning may, for some carers, be sufficiently supportive; and for others, could provide additional information to contribute to the formal assessment for ACSP.

Assessment and information gathering should be a shared responsibility in a process that should involve carers, practitioners and carers representatives as appropriate.

Appropriate, relevant timely information and communication are needed, so carers know what is available and what their options are.

There should be ongoing contact with the Assessor/Reviewer to make sure changes in carers' circumstances are taken into account in their plan.

Systems (including forms and paperwork) need to be as simple, accessible and user-friendly as possible.

There is a need to look at the carer and the person they care for together, in a flexible way and personalised to each individual concerned.

When there are conflicts of interest that cannot be resolved between the carer and the supported person then it may be in their interests to have separate assessments with different assessors.

It is thought that lower numbers of ACSPs may indicate carers' needs are being met out with the formal ACSP system. There is concern that a higher number of formal ACSP may be misinterpreted as an indicator that a local authority is supporting carers well.

KEY MESSAGES

Duty to set Eligibility Criteria

Carers identified that the draft Eligibility Criteria were valid and seem to provide an appropriate basis for determining eligibility.

The common view from focus groups and interviews was that all carers should have easy access to good quality supports that maintain, sustain and improve their lives.

Overall the draft Framework and Framework diagram makes sense and seems a fair approach to supporting carers to meet their outcomes.

Although most of the recorded comments agree with the framework's outcome-based approach to support carers there were a variety of views from carers about which carers should be entitled to additional support.

Carers felt that there should be a combination of some help to all carers and additional support to carers who need it most.

Duty To Provide Support

Carers Support should be personalised and carers should have choices about the support they receive, who provides it and when they receive it.

Under the power to support carers, carers should continue to have access to good quality supports that maintain, sustain and improve their lives without having to have an ACSP and a need to be assessed for eligibility.

Some carers seem to be confused about support funding (budgets) and income. This makes some carers anxious about the Carers Act and support planning. They are particularly worried that changes will affect benefit entitlements or mean extra charges for them or the person they care for.

Although some carers felt that carers' funding should not be used in place of the supported person's own budget/support, others disagreed but thought it need careful monitoring to make sure carer was not disadvantaged.

If local arrangements are made that allow Carers 'Personal budgets' and the personal budget of the supported person to be combined, it is important that the focus is not just on the supported person and that carer health and wellbeing are considered.

KEY MESSAGES

Duty to Provide Short Breaks Service Statements

Care and Support Planning needs to be done together with carer, supported person and assessors, with a joint responsibility for ensuring breaks are in place.

When care packages are designed for the person who needs care and support these should include care support that allows carers to have a break in care.

If the care for the person isn't right, then the carer can find it difficult or possibly impossible to have a short break.

Services and information about options need to be accessible and available when needed.

Having to pay for respite services and provision, whether it's the carer or the supported person, is a barrier to carers getting a break.

Some carers said any carer contribution should be voluntary and not means-tested. Carers who responded to the consultation indicated that they would consider a voluntary contribution.

Many carers said if the purpose of the respite care is to relieve a carer, there should be no charge to anyone.

Carers recognise that quality care is available, but nothing can replace the care that they provide.

THE CARERS ACT

The Carers (Scotland) Act (2016) introduces new rights for unpaid carers and new duties for local councils and the NHS to provide support to carers. The Act will come into force on 1 April 2018.

The Act introduces a number of new provisions to identify and support carers. These include:

- Carers Assessments will now be replaced with ACSPs and Young Carers Statements (YCS). These will be available to all carers at their request. (Adult Carers are defined as being at least 18 years old. Young Carers are defined as being under 18 years old, or 18 but are still pupils at school).
- ACSPs and YCS will help identify carers' personal outcomes related to their caring role.
- The ACSP and YCS will identify if a carer is eligible for support against local eligibility criteria.
- Carers who do not meet eligibility criteria will still receive help and can access services such as information and advice from local councils and local carer support services. Carers may also be offered support such as breaks from caring.
- The ACSP and YCS for anyone caring for someone with a terminal illness will be expected to be completed within a specific time limit.
- The NHS will be required to inform carers and take account of carers' views in making decisions relating to hospital discharge for the person they care for.

In preparation for the enactment of the Carers (Scotland) Act in 2018, the Scottish Government allocated funding for pilot projects to inform local and national implementation. DHSCP carried out a pilot project between May and October 2017. The aims of the project were to explore how the Act could best be implemented to support carers to achieve their outcomes.

This report presents the learning from that process and shares the information that we learned from local people, including carers, carers organisations and statutory bodies.

BACKGROUND AND METHODOLOGY

Background

The pilot project aimed to test out four provisions of the Carers (Scotland) Act:

Section 6-9	Duty to prepare ACSP including content required in ACSP
Section 21	Duty to set local eligibility criteria
Section 24	Duty to provide support
Section 35	Short breaks services statements (SBSS)

The anticipated outcomes of the project were that through co-production Dundee Carers Partnership would be able to:

- Ensure that the Dundee ACSP document records information and provides content required in the Act.
- Co-produce agreed eligibility criteria with carers and stakeholders.
- Involve carers and stakeholders in setting the eligibility threshold.
- Be clear about who is responsible for funding the care of the person when the carer needs respite/relief/short break.
- Make recommendations for a local Short Break Service Statement.

Methodology and process

The group used the National Standards for Community Engagement as a reference.
http://www.scdc.org.uk/what/training/voice-online-tool-community-engagement/

During its first meeting, the Project Implementation Group identified some principles to guide the Project and generate open and honest dialogue about the Act:

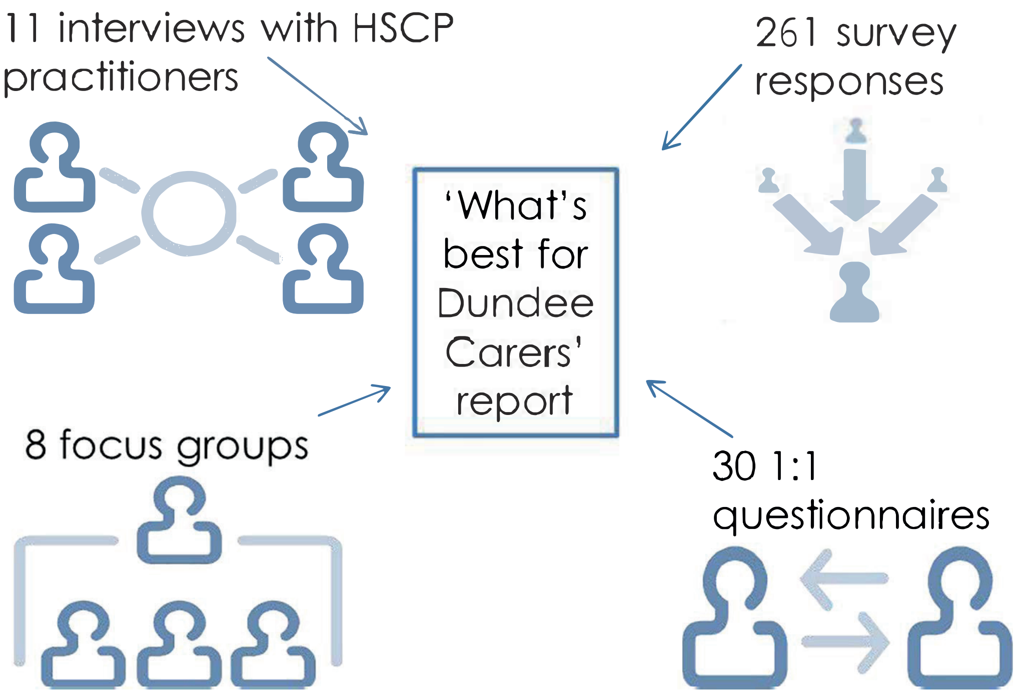
'We must include carers and workers on an equal footing. Everybody has something valuable to offer – we need to encourage and support people to share their ideas with us, and give them time to do so. We can share learning from other areas e.g. localities. As carers and practitioners, we should work together to plan and run events, as this will help us give and get information more effectively. We need to show 'what's in it for me' – why should carers and practitioners take part in our work? We need to be as inclusive as possible, e.g. thinking about communications needs and equalities. We'll make efforts to reach carers of people with different conditions.'

The process consisted of three main stages, each of which was designed to be inclusive of carers, practitioners and others:

- Project design
- Information giving, consultation and engagement
- Data analysis and report planning.

METHODOLOGY

The group identified that the Project needed breadth (reaching as many people as possible, generating quantitative information) and depth (going into detail and generating qualitative information). To achieve this, a mixed method approach was chosen. This used different channels and tools for different purposes, as part of a coherent overall plan:



- A survey sent to over 2500 people, elicited 261 responses on stakeholders' awareness of the Act and their information requirements.

- 6 community focus groups, consulting 29 carers and supported people on SBSS and the Duty to provide support to carers. (NB The Implementation Group used the term Supported Person in preference to 'cared-for person'. This term includes people with a carer as well as those who do not have a carer).

- 2 focus groups (totalling 15 carers) were held with specific Black and Minority Ethnic (BME) Carers where the survey questions were discussed and replies and discussions recorded.

- 11 Health and Social Care Partnership (HSCP) Assessment and Care Management practitioners were interviewed informally, focusing on SBSS and ACSPs. Two email responses were also received.

- 30 1:1 questionnaires were completed along with carers on the Dundee Adult Carer Outcomes framework and documentation (eligibility criteria).

SURVEY SUMMARY

47 people also volunteered to help review ACSP documentation, but the process was not fully completed in time for inclusion in this report although some constructive comments have been received.
The Project design reflects the Project Implementation Group's commitment to genuine co-production:

- Identifying requirements of and engagement with specific equalities groups, including BME carers and those with sensory impairments.
- Preparing background information on the Act to accompany surveys, focus groups and interviews. This included: a Carers Act Summary; 'Jargon buster' glossary; PowerPoint presentation; case studies and Short Breaks definition.
- Arranging an input to the Project Implementation Group from Shared Care Scotland about replacement care.
- Supporting Project Implementation Group members to facilitate focus group activities as part of community consultation events.

Some reflections on the co-production process are shared in the section on **Project Implementation Challenges and Learning.**

Survey summary: respondents

Overall there were 261 survey responses. 196 survey respondents identified as unpaid carers; 61 were not carers.

212 respondents care for someone in Dundee (including 27 who did not identify as unpaid carers). These 27 people may have been responding in a role other than carer because the survey asked people to identify which capacity they were responding in, rather than their identity or role.

108 work in Dundee, 143 do not (most likely indicating that they do not work rather than that they work elsewhere).

20 respondents work for the NHS or local authority. 7 work for third sector organisations. Together they account for 10% of respondents.

23 respondents identified as having a disability or health condition, 4 of whom were also carers. The majority (75%) of survey respondents identified themselves as carers in Dundee. Some of the respondents who identified as carers had other work roles or disability/health needs themselves.

Chart 1: Are you an Unpaid Carer?

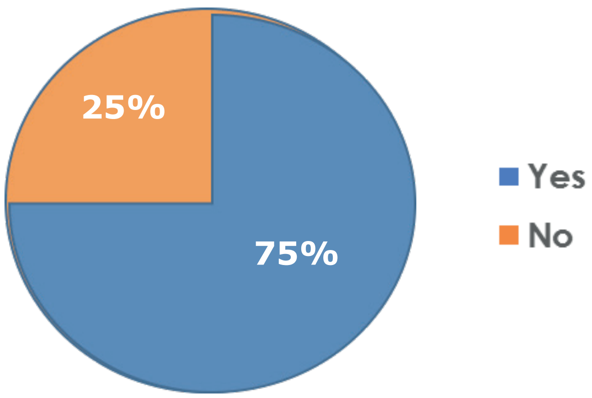
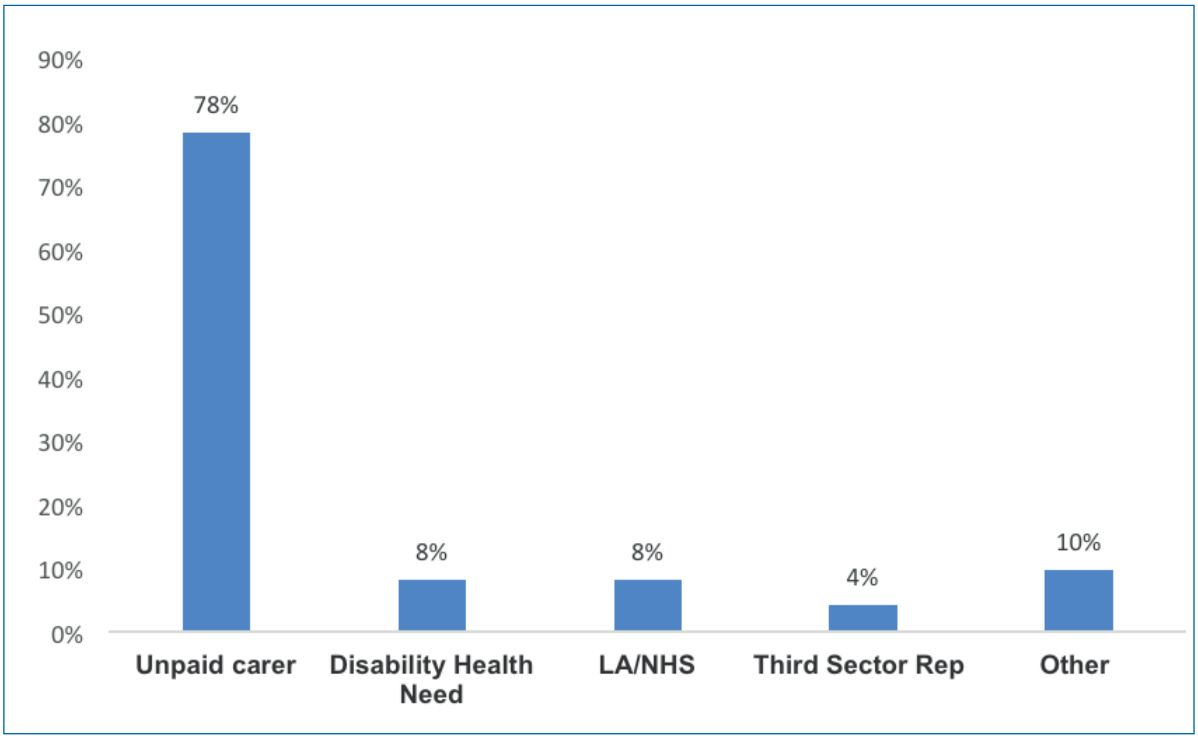


Chart 2: Are you replying to this survey as?

The survey respondents further identified the role they were responding in. There was some diversity in respondents, though practitioners were not as fully represented in the Project as had been anticipated by the Project Group.



Other includes former carers and people whose role was described as parent

Duty to provide support to Carers

The Project explored the Duty to provide support in depth through six focus groups with 29 carers and supported people, and 11 practitioner interviews. Carers and practitioners were generally in agreement over a several core themes:

- Carers should have access to good quality supports, without the requirement for assessment, ACSPs or eligibility criteria.
- Systems need to be as straightforward an un-bureaucratic as possible.
- Funded support should be available for those who need it most.
- More work is needed to clarify the relationship between income (personal or household) and budgets.

These themes are explored below.

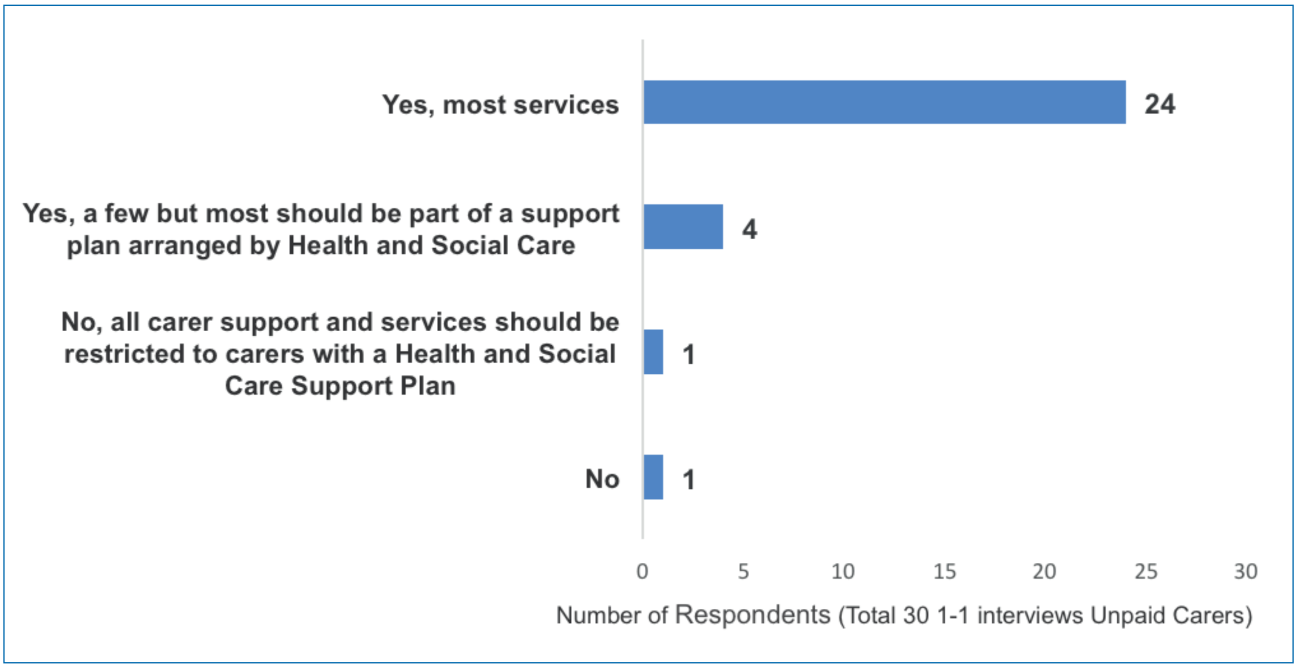
24 out of 30 carers said that there should still be supports and services that carers can access directly by themselves. Only 4 thought that there should be a small amount of direct access service but most should be part of a support plan arranged by Health and Social Care. One person thought no service and supports should be offered for direct access and another said all carer supports and services should be restricted to carers with a Health and Social Care Support Plan.

CARERS SUPPORT AND SERVICES

The common view from focus groups and interviews was that all carers should have easy access to good quality supports that maintain, sustain and improve their lives.

Duty to set Local Eligibility Criteria

Chart 3: Dundee Carers Partnership currently offer support and services that carers can access directly by themselves should there still be these kind of services and support?



Carers in focus groups were in agreement with those in the one to one interviews.

> *'Continue with universal services so people can access without a support plan or outcomes assessment.' (Carer in focus group)*
>
> *'Shouldn't have to do paperwork to access support and help, if you have it already it should still be accessible - shouldn't be creating more stress for carers.' (Carer in focus group)*

Under the power to support carers, carers should continue to have access to good quality supports that maintain, sustain and improve their lives without having to have an ACSP and a need to be assessed for eligibility.

Duty To Provide Support

Systems (including forms and paperwork) need to be as simple, accessible and user-friendly as possible.

Duty to prepare Adult Carer Support Plan

ADULT CARER SUPPORT PLANS

Who completes the assessment with the carer?

Currently in Dundee Formal Carer Assessments and Support Plans are undertaken by colleagues in Health and Social Care Partnership and Dundee City Council.

Some practitioners reported feeling that statutory services may not always be best placed to support the carer or complete the ACSP. For example, support from some teams may be very short term, so longer-term support plans could be difficult for the same team/practitioner to review.

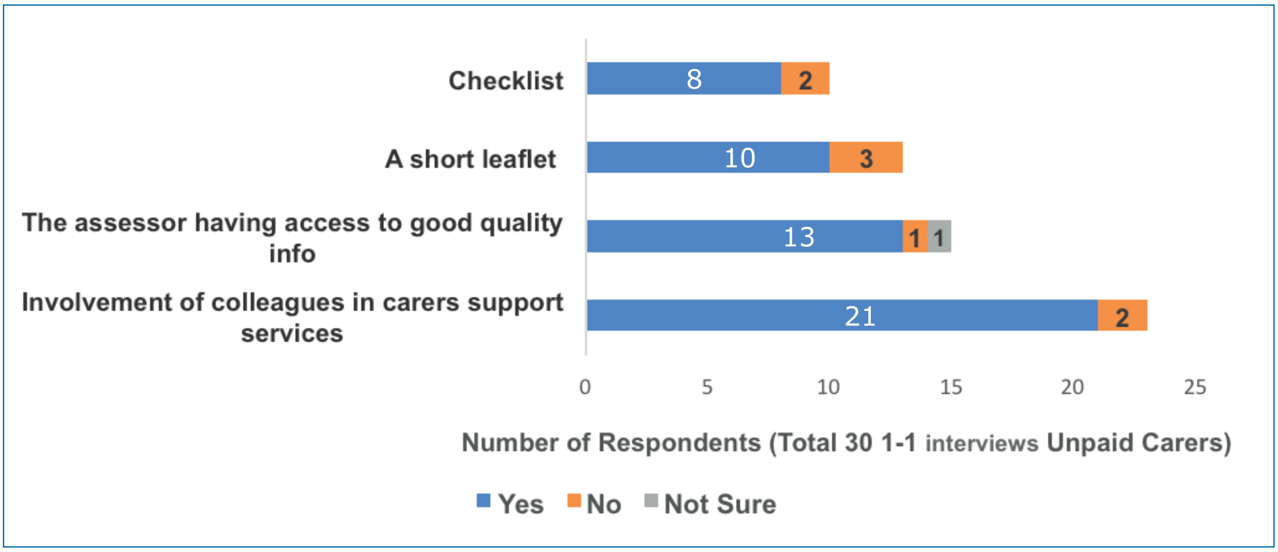
Carer focus groups came to the conclusion that there should be regular contact to make sure changes in carers' circumstances are taken into account in their plans:

> *'Contact may be an issue, (so) you know if you are getting enough support if your circumstances change.' (Carer in focus group)*

Some practitioners suggested the Carers Centre undertake the Assessment and ACSP on behalf of the Council/Health and Social Care Partnership. While some Carers Centres in other areas have contracts to do this, there are questions about what this means for the independence of the support they can give. Assessment and support planning are and should remain part of good working practices. They are a shared responsibility, in a process that should involve carers, practitioners and carers representatives as appropriate.

In 30 one-to-one interviews, carers expressed a strong preference for carer support services to be involved in the support planning process and emphasised the importance of the assessor getting good quality information. They also thought it would be helpful for the carer to have more information for the carer in the form of a checklist or brochure.

Chart 4: The importance of carer support services and good information in support planning



ADULT CARER SUPPORT PLANS

Informal assessment and planning may for some carers be sufficiently supportive and for others could provide additional information to contribute to the formal assessment for ACSP.

Duty to prepare Adult Carer Support Plan

Assessment and information gathering should be a shared responsibility in a process that should involve carers, practitioners and carers representatives as appropriate.

Duty to prepare Adult Carer Support Plan

There should be ongoing contact with the Assessor/Reviewer to make sure changes in carers' circumstances are taken into account.

Duty to prepare Adult Carer Support Plan

Information

Appropriate, timely information and communication are needed, so that carers know what is available and what their options are. Focus group participants noted that information-giving is a process - it should continue over time. It should also be available informally:

> *'More info available about what universal services are available particularly at time of receiving diagnosis.' (Carer in focus group)*
>
> *'Having access in an informal way is the best support for carers, people need help there and then – can't be too formal.' (Carer focus group)*

A theme that also came up in some of the question responses, was that carer support plans should be flexible, adapting to changes in the caring role:

> *'Formal support plan – should be flexible and not rigid, especially if caring role is in flux.' (Carer in focus group)*

Appropriate, relevant timely information and communication are needed, so carers know what is available and what their options are.

Duty to prepare Adult Carer Support Plan

Paperwork

Carers and practitioners were both strongly of the view that any forms and paperwork need to be as simple, accessible and user-friendly as possible.

> *'It should be kept simple, should be able to access help without a carer support plan.' (Carer in focus group)*
>
> *'Carers will not be best supported through overly bureaucratic systems.' (Practitioner interview)*

Practitioners were also concerned that record keeping and documentation could become their primary task, rather than supporting carers.

> *'Carer Support Planning is just another priority among many and it will be difficult to prioritise this in a context of trying to secure support for people, Adult Support and Protection and Incapacity Act Work. This can be overwhelming.' (Practitioner interview)*

Focus groups asked whether carers should get additional support plan funding to achieve their outcomes where the available support does not meet their needs.

Carers' responses indicate that they may be confusing support funding with income (even though the question was asked immediately after a presentation about the way that funding for support plans could work). Carers are evidently anxious about support planning, worrying that changes will affect benefit entitlements, or mean extra charges for them or the person they care for. There was a clear view that many people would refuse support if they thought it would affect their income, or if they felt they didn't 'deserve' it:

> *'A lot of people won't apply as they may be worried it affects their money/benefits.'*
> *(Carer in focus group)*

> *'Some (carers) feel as they're managing financially they would not ask for additional funding.'*
> *(Carer in focus group)*

As noted, it will be important to provide clear, consistent, personalised information so that carers fully understand their options.

Some carers seem to be confused about support funding (budgets) and income. This makes some carers anxious about the Carers Act and support planning they are particularly worried that changes will affect benefit entitlements or mean extra charges for them or the person they care for.

Duty To Provide Support

Adult Carers Support Plan Funding (Carers Self-Directed Support Budget)

Carers in the focus groups were asked 'Do you think carers should be able to use ACSP funding towards support for the person they care for?'

This generated a range of views from carers. Some carers felt that carers' funding should not be used in place of the supported person's own budget/support:

> *'It should come out of the person who needs care, as a break is when you are out of the house not having to think about day to day life.' (Carer in focus group)*
>
> *'It should already be in the cared for person's plan.' (Carer in focus group)*

Although some carers felt that carers' funding should not be used in place of the supported person's own budget/support others disagreed but thought it need careful monitoring to make sure carer was not disadvantaged.

Duty To Provide Support

Others were in favour of using carer support funding towards the person they care for, noting the joint impact that carer support can have:

> *'(I) should be able to use my funding as a carer for supported person e.g. contributing to pay to take supported person on holiday with them – family holiday.' (Carer in focus group)*

However, the risk was also identified that, given the choice, some carers would prioritise the person they looked after over their own needs:

> *'Carers won't use the budget for themselves.' (Carer in focus group)*

Overall, there is a need to look at the carer and the person they care for together this must be flexible with support being personalised to each individual, and with genuine choice for carers.

> *'We need to look at the carer and the cared for person together to see what they need.' (Carer in focus group)*
>
> *'It has to be flexible as everyone is different and circumstances are different.' (Carer in focus group)*
>
> *'Why is there not one document for each service user including carers plans?' (Practitioner interview)*

However, one practitioner raised the issue of conflicts of interest, leading back to the question of the most appropriate practitioner to complete carer assessments with carers:

> *'If (the same) practitioner completes service user assessment and carer assessment what about potential conflicts of interest?' (Practitioner interview)*

Carers Support should be personalised and carers should have choices about the support they receive, who provides it and when they receive it.

Duty to set Local Eligibility Criteria

There is a need to look at the carer and the person they care for together, in a flexible way and personalised to each individual concerned.

Duty to prepare Adult Carer Support Plan

When there are conflicts of interest that cannot be resolved between the carer and the supported person then it may be in their interests to have separate assessments with different assessors.

Duty to prepare Adult Carer Support Plan

In the Focus Groups carers were invited to give opinions about

> 'Should carers and the people they support be able to combine their care and support funding *to get the best for all concerned?'*

The main theme to emerge in response to this focus group question was that people should have choice, depending on their circumstances:

> *'Everyone's personal circumstances are different & this needs to be taken into account.'*
> *(Carer in focus group)*

Personalisation and flexibility to respond to changing circumstances were recurring themes in many focus group discussions:

> *'It has to be flexible to provide give & take for the carer. Have to understand carers circumstances can change at any given moment.' (Carer in focus group)*

Another repeated theme was that both carers' and supported people's outcomes should be taken into consideration, individually and together. If 'personalised budgets' are combined, it is important that the focus is not just on the supported person and that carer health and wellbeing are remembered.

> *'People should have a choice but should be encouraged to make sure that the outcomes for carers are met.' (Carer in focus group)*

If local arrangements are made that allow Carers 'Personal budgets' and the personal budget of the supported person to be combined, it is important that the focus is not just on the supported person and that carer health and wellbeing are considered.

Duty To Provide Support

Eligibility criteria and thresholds

The Draft Outcomes Framework

Dundee Carers Partnership along with local carers and carers organisations began preparatory work on eligibility before the pilot started. This allowed local development to further develop and adapt a model produced by the National Carer Organisations. The Framework is based on principles and research completed by National Carers organisations on a proposal for 'A Framework for National Eligibility Thresholds'. This proposal was not accepted as it was agreed that Eligibility would be set locally.
http://www.carersnet.org/2015/07/give-us-your-views-on-the-national-framework-for-eligibility/

A local framework is proposed that identifies outcomes in four potentially important areas in a carers life which are critical to continuing in the caring role: A Good Lifestyle; Health; Managing Caring; Financial.

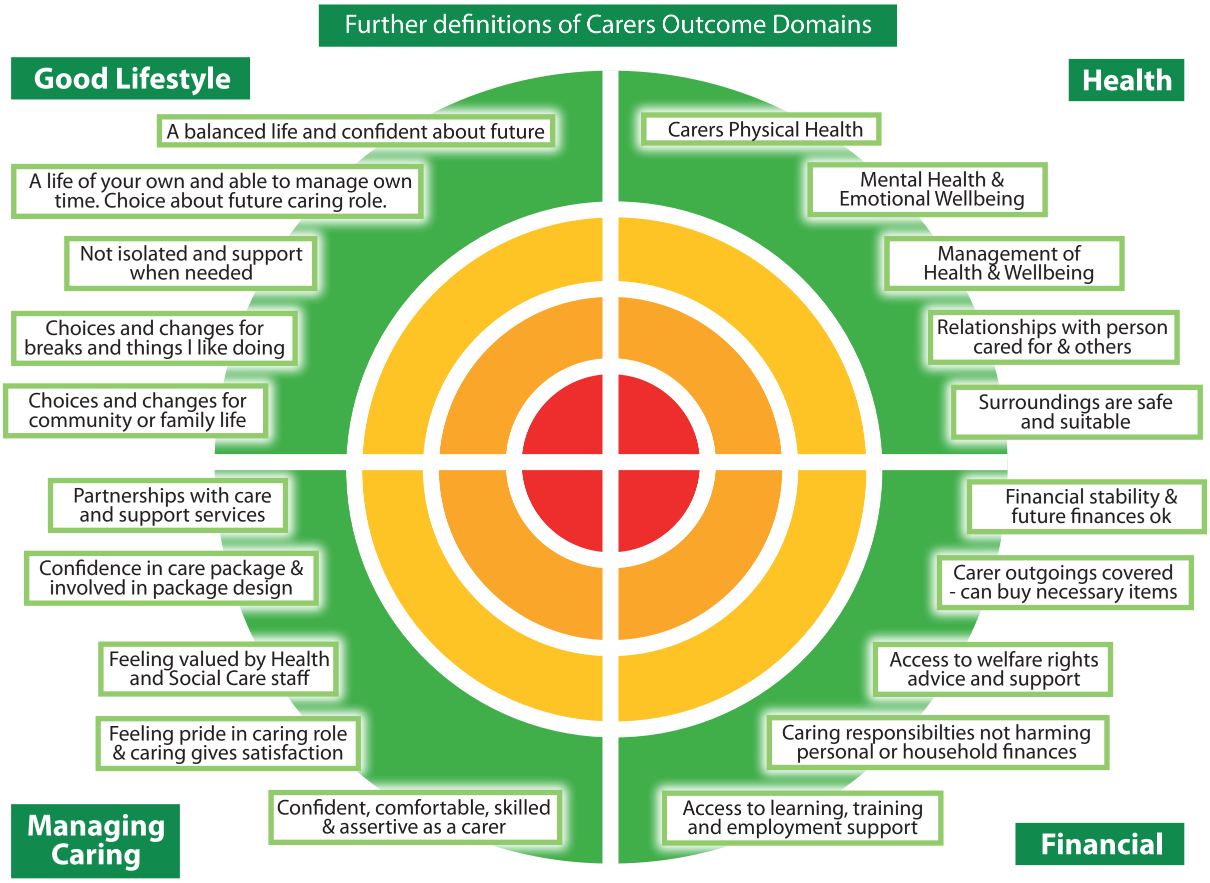


Figure 1: The proposed outcome framework [expanded version with specific suggested outcomes.)

The aim is that all carers should be able to achieve all four outcomes. The risk of the outcomes not being achieved would then be assessed, with the level of risk forming four distinct bands, illustrated by the coloured circles in the diagram above and described in the table below. The proposal is that highest indicated risk in any of the four areas is the indicator for eligibility. For example, if a carer is at red ('critical') in one area, then the risk of them not achieving outcomes is seen as critical even if the indicators in the other outcomes are green, amber or red/amber.

ELIGIBILITY

🟩	No/Low Risk	Caring has no or low anticipated negative impact on achieving carer outcomes. Risk prevention should be considered.
🟧	Medium Risk	It is recognised that caring has a negative or potential negative impact on achieving outcomes. Caring has a small/moderate risk of not achieving outcomes.
▨	High Risk	Caring has considerable impact and there is a high risk of carer outcomes not being achieved unless additional supports are planned.
🟥	Very High Risk	There is evidence of critical impact to carer achieving outcomes. The carer may reach or has already reached crisis point.

Table 1: Risk to carers' outcomes: proposed bands

The proposal is that by April 2018 the HSCP will determine at which "Risk Band" Red, Red/Amber, Amber or Green the Eligibility Threshold will be set. Outcome areas (or domains) are the Eligibility Criteria and the expectation is that the eligibility threshold will indicate if a carer is eligible for a Funded Support Plan. The Funded Support Plan will then be discussed with the carer and the Assessor and the 4 options of Self-Directed Support will be discussed.

The pilot asked carers and practitioners about this proposed framework in 1:1 interviews, (Using Figure 2 below to explain the framework). Firstly, it explored whether the outcome domains were the right ones and whether the diagrams shown here were a good way to describe the framework. Secondly, it asked where the eligibility threshold for a funded support plan should be set. Responses to the two questions are presented below.

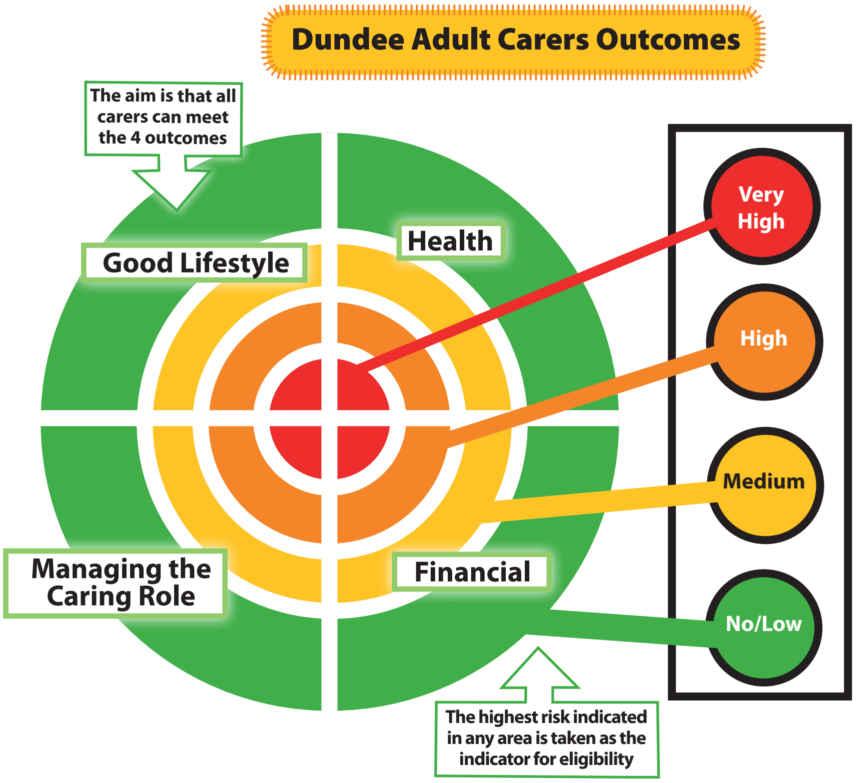


Figure 2: Outcomes and risk combined in an outcomes and eligibility framework.

Carers Views about outcomes in the Framework

28 out of 30 carers indicated that the framework contained all the relevant outcomes for carers.

Two suggestions for what else could be encompassed were:

- *'Managing medication should be mentioned specifically.'*
- *'More support around bereavement and fast track quality emotional support.'*

25 out of 26 carers who answered the question agreed that the framework was a good way to show which carers might need extra support, with 9 out of 11 comments saying that the framework was clear, straightforward and visually appealing.

> 'It's a fair system to get things right for us.'
> 'Good reflection, shows what carers actually do.'
> 'Good framework system, traffic light was clear and easy to understand.'

One carer felt the diagram could be better presented, another correctly identified that the tool should be used as part of a 1:1 conversation, not on its own.

Carers identified that the draft Eligibility Criteria were valid and seem to provide an appropriate basis for determining eligibility.

Duty to set Local Eligibility Criteria

Overall the draft Framework and Framework diagram makes sense and seems a fair approach to supporting carers to meet their outcomes.

Duty to set Local Eligibility Criteria

Eligibility: Which carers should get additional help?

In answer to the question in focus groups 'Which carers do you think should get additional help?' there were 38 comments in total.

Carers expressed a variety of views about which carers should receive additional support. Most of the recorded comments (14 out of 38) agree with the framework's outcome-based approach to support. However, many (13) indicated that carers of people with particular conditions should be prioritised. Other answers and comments are listed below.

14 comments agreed that we should provide 'Extra help for carers who cannot achieve their outcomes with support they can access directly.'

Comments included:

- *'Depending on carers ability given their individual circumstances.'*
- *'Should be targeted depending on needs of cared for person.'*

There were 13 comments suggesting 'Extra help for carers of people with particular conditions e.g. terminal illness, dementia, autism, mental health.'

Comments included:

- *'If there are mental health challenges as well as other needs.'*
- *'Varies on needs of carer, e.g. High functioning autism gets missed and falls between cracks.'*

Some carers (7) thought 'Every carer should get exactly the same support'

Some comments were slightly contradictory:

> 'Same for everybody but more for the most challenging IF it will make a difference.'

Two other comments suggested people with more than one caring role should be prioritised for support:

> *'Carers who have more than one caring role should get more support.'*
>
> *'Where more than one caring role - i.e. cared for has a child.'*

Although most of the recorded comments agree with the framework's outcome-based approach to support carers there were a variety of views from carers about which carers should be entitled to additional support.

Duty to set Local Eligibility Criteria

Threshold for additional support through a funded support plan

Most carers (19 out of 30 asked) felt that there should be a combination of additional help to carers who need it most, and small amounts of help to all carers. Reasons for this were fairness, balanced with additional support going where it is most needed.

> *'Find it fair everyone gets some help.'*
> *'Carers who are most in need should get most help.'*
> *'Targeted resources to most needy (means tested.)'*

Practitioners in Assessment and Care Management teams shared similar views, particularly regarding the suggestion of means testing:

> *'The funded support plans should be available for those carers who need it most.' (Practitioner interview)*
>
> *'We need to consider means testing carers, there should be an upper income and savings limit to funded carer support.' (Practitioner interview)*

Practitioners also identified the need for guidance and joint working to make sure carers in most need are identified:

> *'It would be helpful to have guidance that helps identify triggers for the times that a Support Plan would be a benefit to carer.' (Practitioner interview)*
>
> *'In order to prioritise the carers in greatest need other colleagues need to highlight which carers are most in need of additional support – ACSP are unlikely to be completed in discharge planning stage so colleagues need to gather info that helps prioritise and signpost.' (Practitioner interview)*

It is recognised that a range of indicators will be needed to evaluate the impact of the Carers Act. There was concern within the Project Implementation Group about the risk that across Scotland the number of ACSPs might be seen as an indicator of how well each area is supporting carers.

The Project Implementation Group hoped that there would be a way of recognising that there could be areas where there is good early intervention, and preventative universal supports for carers. These areas may have lower numbers of ACSPs because carers' needs are being met out with the formal ACSP system.

It is thought that lower numbers of ACSPs may indicate carers' needs are being met out with the formal ACSP system. There is concern that higher number of formal ACSP may be misinterpreted as an indicator that a local authority is supporting carers well.

Duty to prepare Adult Carer Support Plan

Carers felt that there should be a combination of some help to all carers and additional support to carers who need it most.

Duty to set Local Eligibility Criteria

Short Break Service Statements

> *'I think that short breaks could be one day to several days. They are for carers to pursue activities that they would have normally pursued prior to adopting their caring role, which may now restrict their lives in some way, whether it is going out for a coffee with friends, shopping, a short break (perhaps a bus trip or a couple days away with friends or other family) a break that allows them to relax knowing their loved one is safe and they can enjoy themselves for a time without the physical and mental stresses of being a carer.' (Survey respondent)*

The Carers Partnership and Implementation Group identified two challenges when discussing Short Breaks and 'replacement care'. Firstly, it must be acknowledged that there could be no adequate replacement for what an unpaid carer actually does. Secondly, despite being in more common use for a few years, the term 'Short Break' is still the subject of misunderstanding and confusion. To inform a local approach to SBSS, the pilot sought to explore these two challenges.

Alternative Care when the Carer is not available (Replacement Care)

Carers recognise that quality care is available, but nothing can replace the care that they provide:

> *'There are some amazing organisations out there, but no-one knows the cared for person like their carer/family member.'*
>
> *'No one can replace what a carer does.'*

Carers recognise that quality care is available, but nothing can replace the care that they provide.

Duty to Provide Short Breaks Service Statements

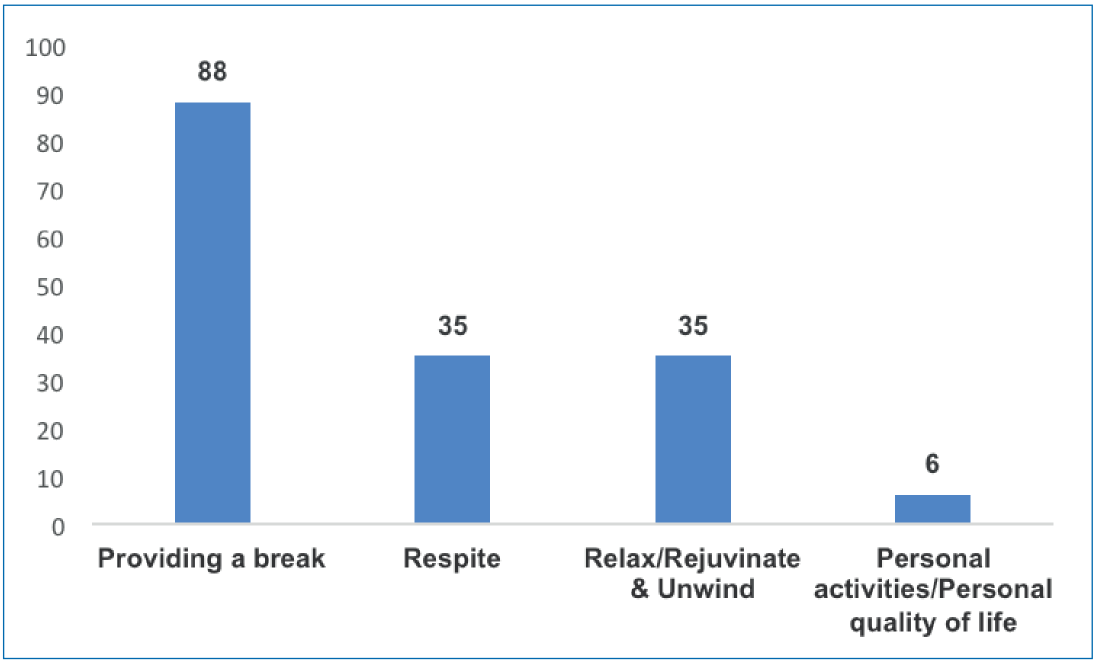
What are short breaks for?

The survey generated 214 responses to this open question, which can be grouped into the following themes:

- Providing a break: 88 comments
- Respite: 35 comments
- Relax/rejuvenate & unwind: 35comments
- Personal activities/Personal quality of life: 6 comments

SHORT BREAKS SERVICE STATEMENTS

Chart 5: What are short breaks for?



There was an interesting diversity of what people see as a break. This indicates an encouraging level of awareness of Short Breaks, following Dundee Carers Partnership's strategy to promote awareness locally since 2012. Most respondents view Short Breaks as benefiting carers, allowing carers to take time away from the stress of their caring role.

Some respondents noted that breaks also benefit supported people. This is important because of the question of charging and payment for Short Breaks (see below).

People with cultural and language barriers thought that bilingual staff and volunteers were a good way to support access to information and services. A common theme across Focus Groups was that there is a need for accessible and easily available information and services.

> *'It can be a minefield to find out what additional care is available.'*
>
> *'Making sure things are transparent - you might not need it now but may need it further down the line.'*

Services and information about options need to be accessible and available when needed.

Duty to Provide Short Breaks Service Statements

Having to pay for respite services and provision, whether it's the carer or the supported person, is a barrier to carers getting a break.

Duty to Provide Short Breaks Service Statements

SHORT BREAKS SERVICE STATEMENTS

What Short Breaks are for?

The pilot generated a good deal of learning about perceptions of what Short Breaks are and are for, as well as ideas about who they are for, and what they are a break from.

Providing a Break

The most common answer to the question of what short breaks are for was that they provide a break. The 88 answers can be further broken down into who the break is for, what the break is for, what it is a break from, and what the outcomes of short breaks are. All of these provide helpful information for describing breaks within a SBSS.

Who the break is for?

44 of the 88 responses stated Short Breaks are for carers. 10 stated they were for both the carer and the supported person, and 23 said they were for the supported person.

> *'Some time out and rest for carer and cared for person. A refreshing break. A change of routine. A change of scenery. A chance to recharge the battery.'*
>
> *'A short break away without worrying about your loved one. To be able to relinquish your caring role to someone else, knowing they will be safe.'*

What the break is for?

> *'Anything which gives the carer a break.'*
>
> *'To help carers get a bit of 'me' time; recharge their batteries. Even an hour to yourself is a short break - it doesn't have to be a holiday which may be impossible for some.'*
>
> *'I think short breaks are for doing the things that you were unable to do when you are caring, i.e. recreation.'*
>
> *'Being given the opportunity for both the carer and the person being cared for to have part payment vouchers available for (e.g.) short city breaks, hotel spa, train journey and anxiety coaching.'*

What Short Breaks are a break from?

Breaks were described as a break from the caring role, the routine, or the stress of caring. Responses were highly individual, so planning Short Breaks also needs each caring relationship needs to be taken individually.

> *'To give unpaid carers a little break away from the caring role. To make us feel like we have a life, to de-stress and to recharge our batteries.'*
>
> *'To provide carer & cared for breaks from one another.'*
>
> *'Getting away from the stress!'*

SHORT BREAKS SERVICE STATEMENTS

Short Break outcomes

> *'Short breaks are about recharging both parties' batteries. They also are a way of meeting the demands of caring for someone long term, when no other options are available.'*
>
> *'Short breaks are for 24/7 carers, to unwind, recharge, and therefore not get ill due to lack of respite. It assists carers to maintain as high a standard of care, given age stage. It is difficult to say what to include: as the carers needs are hugely diverse. The most important thing is to facilitate ease of access to breaks when they are most needed, before crisis occurs.'*

Respite (35 comments accounted in total)

As with the answers above, many respondents emphasised the role of Short Breaks in helping carers and supported people getting time away from their day to day roles and routines. There were also themes relating to carers being able to re-find their own identity and individuality, having 'me' time, restoring mental health and wellbeing and improving quality of life.

> *'Respite, to strengthen and enhance relationships, to promote well-being and relaxation, to recognise the needs and contributions of carers.'*
>
> *'To give respite for both the carer and cared for. To give the couple a holiday together where they can relax and be attended to.'*

However, there is also a need for better respite provision, as noted in a practitioner interview:

> *'In an ideal world, carers (would be able to) to book a holiday and not having to worry about getting a respite bed- we need a better range of positive respite provision.' (Practitioner interview)*

Relax, rejuvenate & unwind (35 comments)

> *'To relax and get a break from caring full time.'*
>
> *'A chance for carers to relax in whatever way helps.'*

Personal activities/Personal quality of life (6 comments)

> *'To provide some 'me time' for carers: e.g. are classes, reading groups etc. Some short courses over a period of a few weeks.'*
>
> *'To offer chance for socialisation and psychological support.'*

When care packages are designed for the person who needs care and support these should include care support that allows carers to have a break in care.

Duty to Provide Short Breaks Service Statements

If the care for the person isn't right, then the carer can find it difficult or possibly impossible to have a short break.

Duty to Provide Short Breaks Service Statements

Charging and payment towards the cost of Short Breaks

The issue of charging and payment for Short Breaks is complex, often generating confusion as well as strong feelings. The pilot explored payment and charging through a number of questions and approaches.

Carers said any carer contribution to costs should be voluntary, not means-tested and that when respite care is provided to relieve a carer, there should be no charge to anyone. The overall consensus from carers and practitioners is that charging makes Short Breaks less accessible, not just because of affordability, but because carers are likely to deprioritise their own needs relative to the person they support. There was also a broader question of whose responsibility it should be to pay.

'As a full- time carer you are not getting a lot of money anyway and receive no holiday pay, so why should they have to pay for their own respite.' (Focus group participant)

Views about charging and payments for breaks

26 out of 28 focus group respondents (carers or supported people) agreed that having to pay towards Short Break costs would mean that breaks would be declined, meaning carers would not get a break from caring roles and responsibilities.

> *'Once people have to start paying, they won't want to have it.' (Focus group participant)*

Practitioner interviews also agreed that breaks/respite should be available without charge and should be available when needed. It was also noted that although flexibility is needed about what constitutes a break, funding still needs to be for a clearly identified outcome and purpose.

> *'Short breaks (respite where the person is cared for) are for carers and should not be charged- I know carers who have no other services and finding it difficult to have respite at home due to lack of services and times that they want as they have to pay the full cost.' (Practitioner interview)*

One additional comment, from the focus group participant who disagreed with the question, suggested a shared responsibility for meeting respite costs.

> *'Government or council/special funds perhaps shared contribution. There is always a cost.'*

Supported people's care plans should include provisions for Short Breaks for carers

27 out of 28 focus group respondents agreed that when a Care Plan for a supported person is assessed and reviewed, the assessor should always make sure that the care package includes provisions that allow the carer to have enough breaks.

> *'If something can be put in place routinely that would be good, making sure the carer gets adequate breaks on a regular occurrence is important.' (Focus group respondent)*

Throughout the pilot, carers and practitioners agreed that planning needs to be done together, with a joint responsibility for ensuring breaks are in place.

> *'(It is the) Care manager responsibility to ensure things are in place for the carer.' (Focus group respondent)*
>
> *'It is a joint responsibility to ensure things are in place/ (there) should be someone else who helps.' (Focus group respondent)*
>
> *'A system that supports a whole system assessment would help- carers funded support and respite care need to dovetail.' (Practitioner interview)*

Care and Support Planning needs to be done together with carer, supported person and assessors, with a joint responsibility for ensuring breaks are in place.

Duty to Provide Short Breaks Service Statements

Carers were asked *'When respite care is to relieve a carer, there should be no charge made to anyone?'*

22 out of 28 focus group respondents agreed that when the purpose of respite care is to relieve the carer, there should be no charge made to anyone.

> *'Respite care should be offered at no charge to carer or cared for person. Life is hard for both if respite is required there.' (Focus group participant)*

Returning to the theme of means testing (see Part 3 above), the view from focus groups was that any carer contribution to Short Break costs should be voluntary and not means-tested. Carers already contribute significantly through providing care, and some carers equate breaks to holiday rights for employees.

> *'People should be given a choice.' (Focus group participant)*
>
> *'Carers are saving the country a fortune, so they should receive holiday pay and entitlements.' (Focus group participant)*
>
> *'Replacement care funding should not come from a carer's budget.' (Practitioner interview)*

Many Carers said if the purpose of the respite care is to relieve a carer, there should be no charge to anyone.

Duty to Provide Short Breaks Service Statements

Carer willingness to contribute to costs?

It is interesting to note that when the question of charging was framed slightly differently (as a way to provide more carers with breaks), carers were more likely to be willing to contribute if they were financially able.

Carers were asked 'To support the aim of offering short breaks as widely as possible would you be willing to make a contribution towards your short break costs or the cost of respite for the person you support?' 11 carers said yes; 10 said no; 3 didn't know; and there were 12 carers with additional comments.

When analysing these results, the Implementation Group noted that services may not have straightforward mechanisms to allow people to make contributions even if they wanted to. And although the overall results are different, the themes emerging from respondents' comments are the same as those presented throughout this section: contributions should be voluntary and dependent on circumstances, charging should not be a barrier, and the responsibility to fund Short Breaks is not a carer's.

> *'While I would be prepared to contribute, finances are often a worry for carers, so I think costs should be covered as much as possible.' (Focus group participant)*
>
> *'It is not a carer's responsibility to make a contribution.'*

Some Carers said any carer contribution should be voluntary and not means-tested. Carers who responded to the consultation indicated that they would consider a voluntary contribution.

Duty to Provide Short Breaks Service Statements

Challenges and learning

What worked well in the Pilot Project?

The staged approach

Taking a staged approach – exploring the four provisions over time and using different consultation methods for different questions – generated good breadth and depth of information. Our flexible approach to engagement ensured carer and practitioner views were heard, despite barriers to participation.

Co-production involving carers

The carers on the Project Implementation Group had experience of taking part in (or running) other planning groups and committees. Their ability to contribute to the design of our survey and events from a carer perspective was particularly helpful in ensuring we gathered the right information in the right ways.

Generating new evidence

Once data had been gathered, the Project Implementation Group had two dedicated meetings to analyse the results and assess their implications. This helped to move the group's collective understanding on, as conversations could be informed by evidence of what local people had said, not just by the views of Group members.

More learning about our processes is given in *Appendix 2: Evaluating our process*

CHALLENGES AND LEARNING

Challenges

Information giving and informed participation

Ensuring people (carers, practitioners and others) were informed about the Act before getting their views was a challenge. The provisions explored in the Project are complex and relatively technical.

To ensure respondents could give informed responses to the pilot's questions, the process needed to inform them about:

- The implications of ACSPs on carers' entitlements – and practitioners' workloads
- The distinction between eligibility criteria and thresholds
- The nature of Short Breaks - and the implications of funding breaks from individual and/or carer budget

To do this without overwhelming people with information, we broke the pilot down into different stages.

Ensuring equal voices in co-production

Our aspiration had been to 'include carers and workers on an equal footing'. However, practitioner involvement in the Implementation Group and in the consultation events were both lower than we would have liked. Another challenging aspect of co-production is that it takes time, particularly at the start, where relationships and mutual trust need to be established.

Overcoming the challenges

Informed participation

Ensuring people were informed meant preparing straightforward briefings (papers, PowerPoint slides etc.), but also giving information in stages throughout the process. We also designed each engagement opportunity around the particular Carers Act provision we were investigating.

Co-production with front line Health and Social Care Partnership practitioners

Engaging assessment and care management practitioners required us to change our methods of involvement and adopt different ways to involve them and get their views. This involved being opportunistic and proactive, creating chances to interview workers informally.

Looking to the future, if practitioners have not been as informed or involved as they could have been in the pilot stage, it may take them longer to engage with and implement the provisions of the Act. The Carer Partnership's workforce development programme, running until April 2018, should mitigate some of this risk.

LOOKING TO THE FUTURE - THE IMPACT OF THE PROJECT

The Project has resulted in a number of actions and is expected to influence the implementation of the Carers Act in Dundee and possibly across Scotland.

1. Scottish Government Carers Policy Branch have been advised of the information and learning arising from the Pilot Project. This report includes the information shared with Scottish Government and some further analysis and information. This report will be shared widely in electronic and printed formats.

2. Events have been arranged to share information with the network of Local Authority and NHS Carers Leads and Social work Scotland Carers Leads.

3. Information will also be shared with Carers and Carers Organisations across Scotland.

4. Dundee HSCP will consider the Key Messages when implementing the Act, with further work to be completed in a number of areas including the ACSP; Eligibility Thresholds; the Duty to provide Support and the Power to support local carers.

5. Dundee HSCP and partners will consider the information in the report in relation to the Short Breaks Service Statement and what further work needs to be undertaken in order for the Statement to be completed by December 2018.

6. The Dundee Carers Partnership Communications Group has been initiated to ensure Carers and those who support them will have good quality accessible information and advice about the rights, and about services and supports to meet their outcomes.

7. Dundee Carers Partnership will be asked to consider setting up a Task Group to consider implications for carers of charging for respite services.

8. The Pilot gathered both qualitative and quantitative information some of which was designed to enhance and inform planning in a wider way than the provisions of the Act. Information gathered from the Project along with analysis and reflections about the information will be subject to further analysis. This will inform future discussion and actions include sharing and promoting our learning about this model of co-production and other matters.

APPENDIX 1

Appendix 1: What support do carers in Dundee want?

To help understand what support carers want, the survey asked the open question *'What support services can we offer unpaid carers in Dundee?'*

The themes to emerge are listed then illustrated below, but it should be noted that many comments could not be grouped into themes, for a variety of reasons. In some cases the question was deemed irrelevant because the person the carer looked after was now in residential care. Some respondents didn't know what other support could be given, and 13 people indicated that they are happy with existing services, with comments like these:

> *'Just to keep doing the fantastic jobs you are already doing.'*
>
> *'All the things you do now.'*
>
> *'Keep doing what you do it's good and informative.'*

To ensure the pilot took in the views of other carers who might not be able to access the survey, some of the questions were also explored in focus groups with specific carers groups, including a BME group who identified other support needs to those listed below .

- A lack of services in the community for men.
- Listening services for the people they care for in their own language.
- Advocacy support for when people are meeting with professionals
- Sometimes there is too much reliance on the family when services should be provided.
- Could services be provided on a one-off emergency basis e.g. if you get ill and can't get your shopping.
- An out-of-hours helpline or emergency contact.

Themes emerging from survey: What support services can be offered to unpaid carers in Dundee?

- Advice, information & sign-posting: 27 comments
- Respite/Short Breaks: 16 comments
- Talking to somebody outside of the family: 16 comments, of which:
    - Peer support: 10 comments
    - Counselling and emotional support: 6 comments
- Social activities and recreation: 13 comments
- Group support: 9 comments
- Financial: 7 comments
- Fitness and weight management: 4 comments
- Anything to reduce isolation: 4 comments
- Information on aids and adaptations: 3 comments

APPENDIX 1

Social activities and recreation (13 comments)

> *'Drop in facilities or classes for cared-for persons to allow carers short term free time to shop, attend exercise class, enjoy a massage etc.'*
>
> *"Places for carers to socialise in a relaxed environment.'*

Group support (9 comments)

Two of the most common needs identified in the pilot were for carers to have better access to information, and for them to feel less isolated in the caring role.

Group support was described as supporting both of these:

> *'I feel isolated it would be helpful if there was some place for people like me to go and talk with other people in the same position as me. I work fulltime and care for my mother I'm exhausted all the time.'*
>
> *'Support re signposting for support groups, activities, etc. More groups for young carers.'*
>
> *'Support groups for carers with children.'*

Combating isolation through group support was also suggested in a practitioner interview:

'There are some services who have tried to reduce feelings of isolation of carers by developing groups, this appears well received so I would suggest a more coordinated approach to carers groups, and widen the opportunities to attend a carers group which isn't condition led.' (Practitioner interview)

Financial support (6 comments)

Some of these comments, related to getting financial advice and support, but two were about having help to pay for respite.

> *'Someone to look after the person, to (let me) go down the town for a couple of hours to pay bills and other things, it cost me £56 for three hours, you can't pay that all the time.'*
>
> *'Help with finances and coping with difficulties of my own. I feel someone should be caring for me!'*

Anything that reduces isolation (4 comments)

Survey responses indicated a high level of feelings of isolation among carers:

> *'Regular inclusion to prevent isolation & feeling bad.'*
>
> *'Just a visit now and then to see how you are managing.'*

APPENDIX 1

Fitness and weight management (4 comments)

Although there were several comments relating to services to improve health and wellbeing generally, four specifically mentioned providing services to improve diet, exercise or weight loss.

> *'Weight management and fitness classes.'*
>
> *'Help them with relaxation, diet, and exercise.'*

Information on aids and adaptations (3 comments)

Three specific requests were made for help with information on equipment to make caring easier.

> *'How to get shower ramps etc.'*
>
> *'Make sure all apparatus is in place which is needed.'*

Appendix 2: Evaluating the Process

Co-production

The Project Group was quite fluid with some participants involved in every meeting about the project and others only one. Discussions took place out with formal meetings either by phone, email or meetings with a few members. Some participants carried out focus group activities, others analysed replies. Each member contributed the input that their time, expertise and skills allowed and respected each other for this. No one person carried out every activity. This allowed the project to progress rapidly and effectively in a way that wouldn't have been possible had the activity all been the responsibility of one person or one agency and contributed to its success in getting a breadth and depth of local involvement and views.

Practitioners involved in the Project were asked what advice they would give to other people to help prepare for the Act.

The main theme was that co-production is time consuming but invaluable:

> *'It's worth every bit of time to take the time needed and involve everyone.'*
> *'Involve carers! More of the 'same' isn't going to work.'*

Carer views also emphasise the importance of involvement:

> *'Get as much input as possible and cover as many carers as you can (it is their Act).'*
> *'Ensure involvement of as many diverse groups as possible. Give opportunity for discussion and feedback.'*

Carers involved in the Project have subsequently agreed to present their experiences of participatory, co-productive working at the Carers Centre AGM in October 2017.

The pilot project has opened other opportunities to allow co-productive work to continue. One method under consideration is the setting up of a carers communications group to support the Carers Partnership Communications work stream, drawing on the positive impact co-production had on the Project.

Information giving

Information-giving is a crucial part of consultation. Using the survey to gauge people's need for information about the Act was useful. Members of the Implementation Group helped facilitate the events. Our 'jargon buster' guide, slides and case studies helped demystify the complex topics, and can be shared with other areas of the country to help their consultation and information giving processes.

Supporting participation

Carers sometimes brought their own current personal concerns to consultations. In future, more thought needs to be given as to how to support any needs that arise, as carers may need to use events for impromptu support when it is available.

The Implementation Group's own participation benefited from independent facilitation to allow people's skills, knowledge and experience to be shared.

APPENDIX 2

Benefits to Participants on the Implementation Group

The benefits reported by carers related to improving their understanding of the Act.

> *'(I got the) opportunity to learn more about the Act. Finding out about the variety of support groups.'*
> *'(I got) more in-depth insight to the Act and process, for gathering information.'*

Carers felt the process was inclusive of their views, and that everything possible had been done to support inclusion, both in the group and through the consultation processes.

> *'There was an equal chance for both sides to contribute (practitioners and carers).'*
> *'All views were looked at with the same respect.'*

Benefits to practitioners on the Implementation Group

The benefits reported by practitioners centred around understanding more about their own role in implementing the Act, and on having established stronger relationships with counterparts in other sectors. They also reported a strong belief in the benefits of co-production, despite the work and time required.

> *'Amazing what a co-produced venture can achieve with hard work and commitment – very refreshing.'*
> *'Improved working relationships across sectors involved.'*

The processes that were found to be useful were having an open forum, and independent facilitation/chairing.

> *'Felt open and equal with great facilitation (that was vital).'*
> *'An environment to share ideas, develop them and strengthen them.'*

Practitioners felt the group could not have done any more to live up to its aspiration to include carers and practitioners on an equal footing.

There was also a shared view that more people could have been included in the pilot, particularly equalities groups, if the timeline had allowed it.

> *'More time would allow us to be more inclusive – go to where people are – but (we have) done the best with the time (we had).'*
> *'Tight timeline of the work at times made this a challenge.'*

Dundee Carers Centre
Because We Care

Dundee
Health & Social Care
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