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# Weavers Evaluation Report 2015 – 2016

The Australian Centre for Social Innovation
and Helping Hand

IT'S A tacsi INITIATIVE

Weavers
Support along the caring journey

Helping Hand
new aged care

COGNITIVE DECLINE PARTNERSHIP CENTRE

# Acknowledgements

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In the Community Matters team, Dr Gill Westhorp, Nathan Overbeeke and Daniel Ball designed or contributed to the design of the evaluation and undertook the analysis. Vikki Booth managed the evaluation redesign, conducted all the interviews, undertook the qualitative analysis, and drafted the report.

The majority of this report was drawn from the work of Community Matters and has additional  adaptions and comments incorporated by The Australian Centre for Social Innovation  (TACSI) and Helping Hand.

Thanks to all of these people, without whom this report would not have been possible.

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# Acronyms, abbreviations and terminology

| | |
|---|---|
| **Carer** | Is someone that is living with, caring for and supporting a person with an illness, disability or cognitive decline (Adapted from Alzheimer Australia's Language Guidelines, October 2014). |
| **Local Connector** | A paid employee of TACSI who oversees the functioning of the Weavers program. |
| **Match** | The formal relationship established between a Weaver and a Carer |
| **Promoter** | An individual or organisation that refers (or potentially will) to the Weavers program. |
| **TACSI** | The Australian Centre for Social Innovation established in 2009 it aims to develop, test and spread innovations that change lives. The Weavers program was one of six solutions that arose from TACSI's work looking at great living in later life. |
| **Weaver** | A past or present Carer who provides volunteer support to other Carers through the program. |

# 1 Executive summary

This is the first evaluation of the Weavers program, a social innovation arising from a partnership between Helping Hand Aged Care and The Australian Centre for Social Innovation (TACSI), both based in South Australia. Following extensive consultation with service users and providers in aged care, the partnership received NHMRC funding through the Partnership Centre: Dealing with Cognitive and Related Functional Decline in Older People (CDPC) to develop an alternate model of support for Carers living with cognitive decline or dementia that aims to reduce the stress of caring and increase Carer wellbeing. TACSI had responsibility for implementing the demonstration/action research approach.

While the specific outcomes vary depending on the individual issues and goals of each Carer, some of the main anticipated outcomes for Carers include successful navigation and negotiation of services, taking increased time out for themselves, reduced stress and depression, increased optimism, a decreased sense of isolation, and increased self-efficacy in their Carer role. These outcomes also potentially lead to improved outcomes for the person being cared for, if the Carer, following their involvement with the Weavers program, is able to provide better or more ongoing support for the person being cared for or if they initiate increased support and access to appropriate services which leads to improved quality of care.

The Weavers model was developed using co-design and social innovation methodologies. Following extensive co-design with service users and providers in the aged care and caring sectors, the Weavers peer-to-peer model was prototyped over a twenty week period working with Carers at home, in collaboration with Helping Hand, the City of Unley and the City of Salisbury. This phase enabled adaptations to be made and ideas to be tested, preparing the way for the current demonstration/action research phase.

The overall purpose of the evaluation is to:

- contribute to the continued improvement of the program as it develops over time;
- test and refine the program's theory of change;
- investigate impacts on Carers and Weavers.

Refining the theory of change for the program is expected to contribute to further refining of the program model. The methodology was informed by developmental evaluation and realist evaluation.

The following Carers, Weavers and Promoters participated in the evaluation:

**Table 1: Evaluation participants**

| | Carers | Weavers | Promoters |
|---|---|---|---|
| **Identified** | 14 | 10 | 10 |
| **Agreed to participate** | 13 | 10 | 10 |
| **Male** | 3 | 3 | NA |
| **Female** | 10 | 6 | NA |
| **Couple** | NA | 1 | NA |

Carers were identified as those that had completed a match. Weavers had either completed matches or spent a minimum of 12 weeks in a match with at least one Carer. In regards to Promoters, 5 of these had referred either Weavers or Carers (or both) to the program.

The survey data shows that around three-quarters of Carers were caring for a partner and that a similar proportion reported the cared-for person had 'high care' needs. Almost half of the survey respondents reported high levels of stress, low optimism and feel a sense of isolation. Few respondents selected the most positive category on any of the sections in the three-point Carer Experience Scale, except for 'getting on with the person you care for'. Scores on the Personal Wellbeing Index were in the mid-range (between 4 and 6 on average) on a 10-point scale. While there was a small number of respondents in the pre- and post-survey, those Carers were more positive about having learned new skills or knowledge than having learned about or used new services. A Supplementary Data Report is being prepared which will include additional survey data analysis, to provide further evidence.

It has been a challenge in the start-up of the program to understand what resources and approaches were needed to effectively recruit Weavers and Carers. Throughout 2014 the lower numbers of Weavers constrained the program's growth. The initial smaller pool of Weavers made it difficult to manage Carers and in some cases the Local Connector provided support. Extra resources and new recruitment strategies led to an increase in recruited Weavers and referred Carers .

As of March 2016 there were 12 active Weavers in the program (3 short of the target of 15) and 53 Carers (target of 60) were referred to the program, 35 progressed to a match and 15 had completed the program at the time of the interviews.

Promoters who refer to the program are happy with it. Two of these five Promoters originally had doubts about the program, but once they had an experience with the program they became advocates. This suggests that it is possible that reservations of service providers may be overcome.

Those Carers who engaged in the program found its flexibility and responsiveness attractive. Those who did not engage usually did not because external circumstances prevented it or circumstances changed and they no longer had a need for the support.

TACSI has commenced working on future directions for the program, in discussion with service providers, Carers and others. Future work will consider the learnings from this demonstration program, particularly drawing on the learnings from what it took to increase recruitment and referral numbers, and consider factors such as cost-effectiveness in the business model design.

Weavers in their interviews provided overwhelming support for the responsive, focussed and flexible approach to the program adopted by TACSI and the Local Connector. The Weavers also highlighted the orientation to the role of Weaver and Learning Lunches as important tools for positioning them to successfully undertake the role of a Weaver and for gaining peer and other support. Carers identified just talking to the Weaver as the most important support that Weavers provided, enabling the development of a positive relationship and communication between Weaver and Carer.

The main two outcomes achieved for Carers were increased assertiveness about their own needs and decreased depression (increased emotional wellbeing). There was evidence that the four program pathways identified in the revised program theory were all at work in the program. Among the small number of survey respondents, Carers were more positive about having learned new skills or knowledge than having learned about or used new services.

Outcomes identified for Weavers include: a sense of purpose/meaning (for nine out of ten Weavers); increased confidence (four); social benefit (three); and reciprocity (two). Proposed mechanisms for these Weaver outcomes include feeling valued for their role as a Carer (which they may not have been, when a Carer themselves), and the recognition that they too would have appreciated such support during their caring role.

While there were only small numbers of Weaver-Carer matches to assess at the time of the evaluation, the data suggests the more similar the experience of the Weaver to the Carer, the more successful the match, including achievement of outcomes.

Any organisations implementing the program into the future should consider the learnings from the challenges this demonstration program experienced with Carer and Weaver recruitment. Additional resources were needed to generate referrals and engagement in the program and participation. Consequently, cost-benefit should be a consideration in future. It is possible that increasing credibility and engagement with service providers may reduce resource requirements for recruitment and the program may prove more cost-efficient over the longer term.

Given the positive outcomes and learnings the following is a summary of recommendations:

- continue to explore models that draw from the direct and lived experience of those that are currently in the caring role and consider innovative and alternative options for Carers
- investigate whether Weavers can be purchased as a product through customer led funding such as Consumer Directed Care program and the new Integrated Carer Support Service (currently being designed)
- co-design (designing services in direct collaboration with consumers) approaches are to be applied to learn from community to better target services
- future projects consider recruitment a major component of research

# 2 Introduction

# 2.1 **Background**

Weavers was conceived following consultations during the visit of Dr Alex Kalache (Thinker in Residence – Age Friendly Cities). During this time the inadequacy of respite become evident with people identifying it as one of the key issues related to service provision. In the funding model for aged care the care recipient receives funding directly (this would be the person cared for) the Carer receives funding through a specific program. The issue is that the two funding programs did not connect and therefore support had to be maximised at the service delivery level.

The Weavers program was first developed by The Australian Centre for Social Innovation (TACSI).

Helping Hand, through their previous involvement in the Great Living 6 and as an industry partner of the National Health and Medical Research Council Cognitive Decline Partnership Centre (NHMRC CDPC), worked with TACSI on extensive co-design research in 2011. Co-design involves working with people to better understand their needs and challenges, and trying out new solutions with them in their own contexts. This research, conducted with relevant service providers and over 100 people in caring relationships, supported previous experience that many people were struggling with their caring role and facing a number of challenges, yet there were also many people who had navigated these struggles and were managing well. The Weavers model aimed to connect these two groups and in doing so reduce the stress of caring and improve wellbeing. Prototyping involved an intense testing phase over 20 weeks working with Carers at home which allowed for adaptations to be made to the model and ideas to be tested with Carers. Following the prototyping phase, NHMRC, Helping Hand, and Southern Cross Care provided funding and support for a larger scale demonstration/action research phase to develop the model further and create an evidence base.

The Weavers model was iterated during this phase based on input from participants and partner organisations, and also based on the introduction of key roles and a review of the prototyping phase. In the original research design completed in 2013, the expected total number of participants for this phase was identified as 80-105 (30 Weavers and 50-75 Carers). Liaison with the CDPC working group in relation to operationalising the program shifted the targets in January 2014 to “approximately 15 Weavers and the respective Carers they’ve been matched with (approx 60)”.

The demonstration phase has therefore aimed towards this latter target, with significant emphasis being placed upon demonstrating the integrity and success of the model and approaches used.

In parallel to this, the Helping Hand Aged Care Research and Development Unit prepared a literature review addressing respite care and its effectiveness in reducing a Carer’s ability to support their loved one. Overall this review found that there is, “limited evidence to support assumptions that respite has a significant or sustained impact on reducing Carer burden”, that it appears to be under-utilised, and for it to be effective the following criteria need to be considered:

- Regular (e.g. weekly) in-home or day-care respite options provide Carers with a chance to undertake household tasks, engage with social networks and undertake self-care, tasks which may otherwise be unachievable. This respite is important for long-term sustainability of at home care.
- Carers require social support to make effective use of respite time. Service providers can assist in this through interventions or dialogue with Carers over use of their respite time
- Nursing staff can assist in reducing Carer stress by engaging with Carer’s routines and knowledge of care for the individuals concerned
- Individualised and meaningful activities suited to the cared for person’s abilities help reduce Carer guilt over use of respite care

The Weavers program aims to contribute to this by building preventive/protective factors for Carers, and help them to regain a sense of control and improve 'balance' between the demands of caring and quality of life. The program matches Carers with a Weaver (volunteer) who can 'walk alongside them' to find ways that suit them to cope with the ongoing challenges of being a Carer. Specifically, "people with personal caring experience are recruited, trained, and connected with Carers in their community, helping them: navigate and negotiate support services; mobilise family and friends; increase community connections; address guilt, grief, and loss associated with caring; find ways to look after their own health and wellbeing; and build resilience and hope for the future"[1]. The Weavers program is designed to create long-term behaviour change, equipping Carers with the tools they need to regain a sense of control and adopt new ways to manage the caring journey.

There are a number of roles in the program. 'Promoters' (such as hospitals, Carer organisations and GPs) provide information about the program to Carers and can make referrals. 'Weavers' provide direct support to Carers over a period of at least 12-20 weeks. Weavers may also bring not only their own experience as Carers, but also their work experience in the health and care industries. They are supported in the role by the Local Connector, a paid staff member who encourages referrals from Promoters, facilitates the matches between Weavers and Carers, and provides training and support for Weavers. Weavers are also supported through regular 'Learning Lunches' and an online website, the 'Loom'. They can also contact other Weavers for advice, strategies and support.

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*[1] TACSI website for Weavers accessed 21 March 2016 http://tacsi.org.au/project/weavers/*

# 2.2 Evaluation

The Weavers program has been evaluated using developmental and realist evaluation methodologies. Developmental evaluation is used with programs that have not attained a final form - this is particularly well suited to innovative programs like the Weavers program that are continually growing and improving. Realist Evaluation is specifically designed to understand how and why program outcomes are achieved and why they vary for different people, or in different contexts.

## 2.2.1 Evaluation purpose

The purpose of this evaluation is to:

- contribute to the continued improvement of the program as it develops over time;
- test and refine the theory of change that is reflected in the Weavers program;
- investigate impacts on Carers and Weavers.

## 2.2.2 Key evaluation questions

The evaluation design has three foci, each with its own questions:

1. Recruitment and engagement
    - How has the program gone about recruiting Carers/Weavers and which strategies have demonstrated the most success?
    - Who are the Carers and Weavers and why do they engage?
    - Of those approached to become ‘Promoters’ of the Weavers program, who does and does not becomes a referral point and why/why not?
    - What are the reasons Carers might not engage with this program?
    - What role does this program play in the current aged care sector and where should it best position itself to best meet the needs of Carers?
2. Support for Carers and Weavers
    - What tools and supports offered in the program are most beneficial to those participating in the program? Which, if any, do not provide any benefit?
3. Outcomes for Carers, Weavers and (potentially) the aged care system
    - What are the characteristics of successful matches between Weavers and Carers?
    - How might the support Weavers provide contribute to outcomes (if any) for Carers?
    - What outcomes are generated, for whom (Carers, Weavers, the health and aged care systems) to what extent, in what respects, how and why?

## 2.2.3 Evaluation design process

The evaluation design process involved:

- Initial workshops involving staff from TACSI and the evaluation team to develop the draft theory of change for the program;
- Further meetings to develop key evaluation questions;
- Consultation with Helping Hand about the evaluation design;
- Drafting of evaluation instruments;
- Review of evaluation instruments by TACSI personnel and the CDPC Working Group members;
- Finalisation of the design and instruments.

The original design assumed quarterly data collection over a 12 month period, with data in relation to different stages of the program (promotion, recruitment, matches, and outcomes) conducted in different quarters. The intent was that information about each of these stages could be fed back to the program with very short turn-around times, thus contributing to program improvement on a rolling basis. However, recruitment of Carers was much slower than had been anticipated, and fewer Carers have been recruited than had been anticipated. The original design therefore required significant adjustment (in late July to early August 2015). The methods finally adopted are described below.

# 2.3 Methodology and methods

As noted above, the Weavers program evaluation is informed by realist evaluation and developmental evaluation. These are each introduced below.

## 2.3.1 Introduction to Realist Evaluation

Realist Evaluation (Pawson and Tilley, 1997) starts from different assumptions than other evaluation approaches[2]. Many evaluation approaches operate as though programs are ‘active’ and that the participants who take part in them are ‘passive’. That is, the assumption is that if the program is ‘right’, it will ‘work’ regardless of the situation. Another basic assumption is that ‘the program’ is the same, and will be implemented in the same way, everywhere it is implemented. Appendix  provides further detail on the approach.

## 2.3.2 Developmental evaluation

Developmental evaluation (Patton, 2011) was designed to be used with programs that expect to continue to adapt and change. It expects that as situations change, programs will respond to them, new questions will emerge, and new kinds of information will be required to answer them. It aims to provide rapid feedback to programs about ‘what is happening now’, in order to inform decision-making about how the program should respond or adapt.

A developmental evaluation approach was considered appropriate for the Weavers program because the program is designed to evolve. The program tests each aspect of what it does and how it does it, and changes in response to feedback. It is also expected to be shaped to each community in which it operates. Although the basic principles of the program are expected to be maintained, the ways in which they are implemented may be different. It is intended that the evaluation can contribute to the process of development and, should the program become ongoing, that the evaluation too will adapt over time to suit the changing needs of the program.

## 2.3.3 Methods

The data sources for the evaluation are:

**Pre- and post-program questionnaire for Carers**

Pre- and post-program surveys were conducted with Carers. These surveys were designed to look at change over time for individuals and provide demographic data, making it possible to look at who has been involved in the program. The surveys used in this evaluation were collected during the period October 2014 to January 2016. Additional survey and administrative data collected after this period will be provided in a Supplementary Data Report.

The original survey was adapted during the evaluation period following feedback from the enabling sub-unit in health economics supporting the CDPC. The intent was to include items which have been used in other research into Carer support programs, with a view to being able to compare results for the Weavers program with results reported for other Carer support programs. As a result, some respondents undertook the original survey as they started with the program, and the revised survey on completing the program. This has further limited the number of surveys for which results can be compared over time.

Across the two versions of the survey, 27 respondents provided data. Twenty-three respondents provided pre-program data and ten provided post-program data. Only two respondents provided pre- and post-program data on the same version of the survey. Another four provided pre- and post-program data on different versions of the survey. Fourteen respondents were reported as ‘active’ (that is, not yet have provided a post-program survey). This means post program surveys are missing for 3 Carers who have completed the program. Pre-program surveys are missing for four Carers. Given the numbers of surveys it has been decided that where there has been different pre and post surveys sent to the Carers, and it seems appropriate to do so TACSI is resending the correct survey for Carers to complete if they choose to. The Supplementary Data report will include any new data with correct versions utilised.

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*[2] This description of the methodology was first used in the evaluation of TACSI's Family by Family Program (2012 evaluation report).*

The data presented later in this report provides a look at the information from both versions of the surveys. Where the questions are the same in both surveys (this only relates to demographic data – no other questions were asked in both versions) the data is presented together, otherwise only the data from the applicable survey is presented.

The following table provides a summary of interviews with a more detailed narrative description provided in Appendix:

**Table 2: Summary of interviews**

| Interviews | Total No. | Mode of interview | Segmentation of Interviews |
|---|---|---|---|
| **Promoters** | 10 | Face to face | Referred into Weavers (5) or not (5) |
| **TACSI staff** | 2 | Face to face | Local Connector and significant staff member |
| **Carers** | 19 | Phone interviews | Opted out (6), Completed match (13) |
| **Weavers** | 10 | 9 face to face,<br>1 phone interview | 3 male,<br>6 female,<br>1 couple |

In addition to the above 3 Weavers also participated in a focus group about the supports they received.

**Analytic Methods**

Because of small numbers of respondents to surveys, only descriptive statistics (frequencies and mean scores) could be provided for survey data. Frequencies are also provided for some administrative data that was provided by program staff.

Realist qualitative analysis (RQA, Westhorp, 2008)[4] was used for interview data. RQA involves identifying outcomes that were reported by respondents; identifying causal processes ('mechanisms') that contributed to those outcomes; and identifying contextual factors that affect whether or not mechanisms operate. Contextual factors may relate to individuals (eg carers, weavers, staff), implementation processes for the program, organisations and their ways of working or broader community, social, economic or political factors. Once elements are identified, the relationships between them are identified and the elements are 'woven together' (Pawson and Tilley, 1997) into an explanation of patterns of program outcomes. Formal theories are then used to help explain those patterns. The program theory that was proposed for the program changed over time and so both the original and revised program theories were considered in the analysis, as the revised program theory was not finalised until March 2016 (refer to Section 3.2 in the Weavers Evaluation Report 2015-16). Both theories were therefore used to inform the coding of the context, mechanism and outcomes, and evidence or a lack of evidence was sought against each of the particular identified elements within the theories. Where the qualitative data did not align to any elements in the program theory, additional contexts, mechanisms and outcomes were proposed and described.[5]

**Qualitative data**

All the qualitative interview data was analysed using a realist evaluation approach, including coding for context-mechanism-outcome (CMO) configurations.

## 2.3.4 Limitations

This evaluation draws heavily upon self-report data from Carers and Weavers, which has both strengths and weaknesses. Its value for realist evaluation lies mainly in understanding the 'reasoning' component of processes of change. However, it is also open to a number of forms of error and bias, including 'social desirability' bias. This bias is common, and refers to the tendency to report things that the respondent believes will be approved of or are consistent with social norms, and not to report things that will not. However, in most cases (if the timing worked out) both the Weavers and Carers in a match were interviewed, and so the data may be verified by comparison with the other party. The findings were generally quite consistent across the two.

There are also important limitations to be noted in the analysis of the survey data. For change over time there are two issues. First, there simply were not enough respondents for whom pre- and post-program data was available. Second, as noted above, this was exacerbated by the decision to change the surveys partway through the year.

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[4] *Westhorp, G (2008) Development of realist evaluation models and methods for use in small-scale community based settings. Unpublished PhD thesis, Nottingham Trent University.*

[5] *Pawson, R. and Tilley, N. (1997) Realistic Evaluation. SAGE.*

# 3 The Weavers program

## 3.1 Introduction

This chapter provides background information about the Weavers peer-to-peer program, how it is expected to work and its implementation. The aim is that the reader understands enough about the program to understand the evaluation report that follows.

# 3.2 **Program theory**

The Weavers program aims to address the caregiver's experience, which Bevans and Sternberg (2013) described as "complex and complicated by multiple competing priorities [in which Carers are] often faced with multiple concurrent stressful events and extended, unrelenting stress". Ongoing changes and increasing complexity in government funding and support may well be increasing that stress. Research at Helping Hand Aged Care showed that Carers who receive respite frequently report that, while they welcome the respite provided, it rarely alleviates the stress which they struggle with day to day in their caring role. TACSI suggested co-design as a way to significantly improve outcomes for Carers by involving them in creating solutions. In this program, people with a lived caring experience (Weavers) provide direct support to other Carers. Weavers have an ongoing role in the program's design and modifications, contributing ideas about what Carers may need and what they would have appreciated during their caring experience, in order to help alleviate the stress of caring and improve the wellbeing of people who are Carers. In this program, Carers are the experts, providing their knowledge, experience and time as a resource and enabler for change, while being supported with appropriate training and development opportunities.

The original program theory designed as part of the evaluation is provided in Appendix 8.2. It reflected the components of a realist theory of change and was colour coded to identify: expected outcomes for the Carer (as well as some possible outcomes for the person they are caring for and for the health system as a whole); possible mechanisms (resources and reasoning) by which the outcomes may be generated; and some contextual factors that may influence mechanisms and outcomes.

During the establishment phase of the demonstration program, the program theory was further developed. This included identification and adaptation of appropriate formal theories and practice frameworks to support the work of the program. These theories and practice frameworks, which are embedded into Weaver orientation training and practice, are:

- Adaptive Caring
- Narrative approaches
- Ambiguous Loss.

## 3.2.1 Adaptive caring

Weavers use a set of tools designed to guide Carers through an 'adaptive caring loop' - acknowledging each problem and its effects, identifying ways to address the problem, supporting the Carer to try out these new methods, and reflecting on the outcome. The aim is to equip Carers with tools and ways of looking at problems that create a sense of control and enable them to adapt to the growing needs of their loved one. The original prototype was based more on 'great living', however, because the demonstration research aimed to shift to more sustainable solutions, this approach was adapted. The new theory anticipates equipping Carers with extra capabilities they can draw upon in the long-term.

## 3.2.2 Narrative approaches

A narrative approach seeks to be a respectful, non-blaming approach to counselling and community work, which centres people as the experts in their own lives. It views problems as separate from people and assumes people have many skills, competencies, beliefs, values, commitments and abilities that will assist them to reduce the influence of problems in their lives[5].

The use of the narrative approach with Weavers began as a partnership with the Dulwich Centre. In the prototyping phase, David Denborough met with Weavers and co-designed how this approach could be applied to the Weavers program. One of the techniques that the Weavers program applies is journey mapping which seeks to identify with Weavers and Carers their caring journey and reflects on what they have drawn upon to overcome challenges in the past, where they have found support during the tough times and how they can draw upon these strengths to support them into the future.

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*4 Bevans M & Sternberg E (2013) 'Caregiving Burden, Stress, and health Effects Among Family Caregivers of Adult Cancer Patients.' JAMA, 2012; 307 (4): 398-403*

*5 http://dulwichcentre.com.au/what-is-narrative-therapy/ accessed 15/3/16*

### 3.2.3 Ambiguous loss

This approach recognises that the ambiguous loss often experienced by Carers of people with dementia and cognitive decline differs from the loss and grief of death because closure is not possible and grief cannot be fully resolved until the person being cared for dies. Carers can experience and grieve loss on three levels: losing themselves and their identity in the situation; losing the person they once knew as decline progresses, and losing previous hopes and dreams of a future with that person. This ambiguous loss and grief adds another layer of complexity that can make coping more difficult[6] which one Carer described as 'the long goodbye'. Weavers has been designed to respond to 'the double load' of caring and provide a way to guide people through the emotional as well as practical challenges that come with caring.

### 3.2.4 Four 'jobs to be done' or core needs of Carers to be addressed

Utilising a business model canvas for social change, the four 'jobs to be done' or core needs for Carers were identified around February 2014. These were identified by the program as mechanisms in the revised program theory (refer Appendix 8.3) which merges the original program theory with the new concepts and which was completed in March 2016. (Note that these 'jobs' or 'needs' are not mechanisms in the realist sense of the word and the term 'pathways' has been used elsewhere in this report.) Support from a Weaver leads to outcomes by clearly identifying focus areas with the Carer in relation to the four key areas (services, sustaining things for yourself, emotional support, connecting and gaining support from family and friends). The aim is to increase confidence and abilities in these areas by working with someone who has been there and understands the process. These four core 'jobs to be done' involve helping Carers to:

- navigate and negotiate the service maze;
- stay connected and involve others;
- work through the emotional challenges; and
- sustain things for themselves

### 3.2.5 Anticipated outcomes

While specific outcomes will vary for each Carer, some overall outcomes for Carers proposed in this original theory of change included:

1. taking increased time for themselves
2. decreased stress
3. increased optimism
4. decreased sense of isolation
5. increased self-efficacy in their Carer role
6. decreased depression.

The March 2016 revised program theory in Appendix 8.3 anticipated that certain short-term outcomes would lead to specific medium-term outcomes, as follows:

1. Carer develops a support network ▸ Carer sense of isolation decreases
2. Carer stress decreases ▸ Carer self-efficacy in Carer role increases
3. Carer finds ways to sustain themselves ▸ Regain a sense of control in the caring situation

These may then lead to the following long-term outcomes for Carers:

- Carer wellbeing increases
- Capacity for the Carer to care for a loved one at home increases.

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*[6] Caregiving and Ambiguous Loss: Fact Sheet (2008) prepared by Family Caregiver Alliance and funded by the California Department of Mental Health. Written by Pauline Boss and based on her books, Ambiguous Loss (Harvard University Press, 2000), Family Stress Management (Sage, 2002), and Loss, Trauma, and Resilience (W. W. Norton, 2006).*

### 3.2.6 Proposed contextual factors

Some contextual factors believed likely to affect whether the mechanisms would operate and outcomes would be achieved included:

- time factors such as the number of contacts and the duration of the relationship between the Weaver and Carer,
- whether the people cared for by the Weaver and Carer have a similar disability (e.g younger onset dementia),
- how similar the relationship is between the Carer and the person they are caring for to that of the Weaver and the person they were caring for (e.g. partner or parent/child).

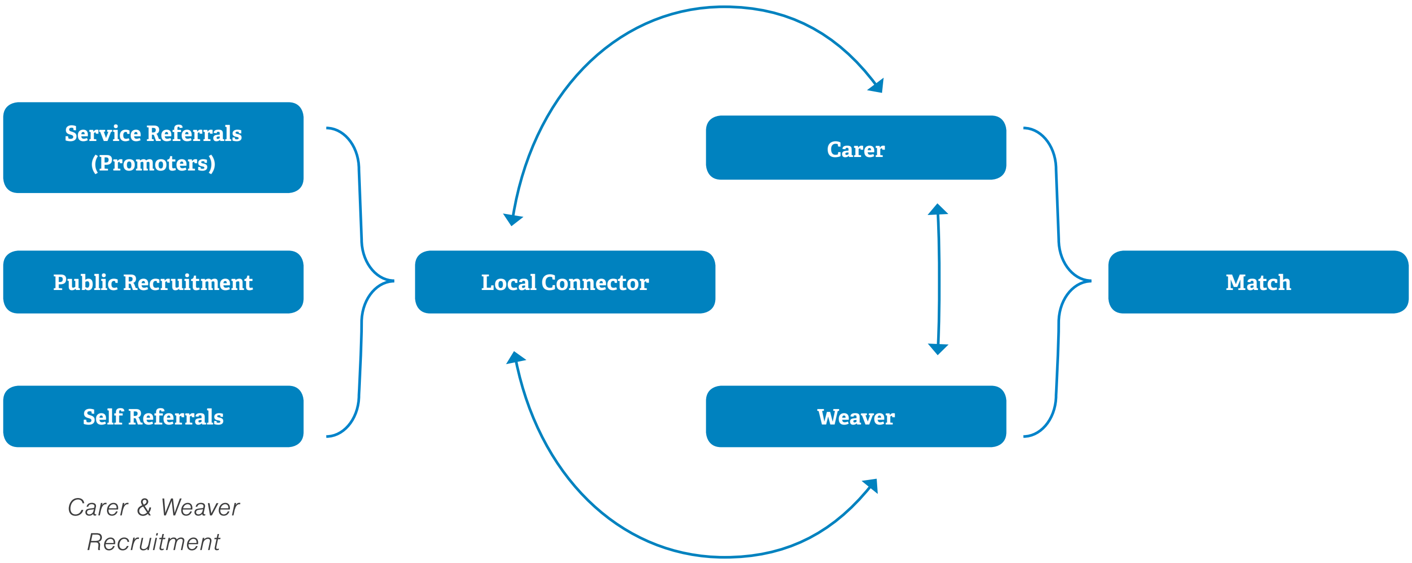
Similarities in the nature of the disability and the nature of the relationship were hypothesised to increase 'shared experience', making it easier to establish a sense of common understanding.

Since the sense of isolation experienced by Carers is considered to be a major factor in health and wellbeing, important elements of the program theory include providing Carers with someone who 'gets it', who is non-judgemental and makes them feel that they're not alone, and helping them to find strategies to engage with services and increase the supports around them.

# 3.3 Program implementation

Following the prototyping phase and receipt of funds from NHMRC, an establishment period commenced from October 2013. In this period, a TACSI staff member was employed to: complete the ethics process; source other funding to support the desired program model; create the promoter network; and renegotiate relationships that had been developed with partners for the new model. The first Weaver training occurred in March 2014 and the first matches commenced around May 2014 (allowing time for Weavers to be fully inducted into the program). The Local Connector (as at March 2016) commenced her role in September 2014, initially part-time and then full time from March 2015. Further support was provided by TACSI, particularly for recruitment, in April 2015. The following figure illustrates how the program was managed and implemented by TACSI. The Local Connector is the central professional role that seeks and receives referrals, supports Carers into a match with Weavers and supports Weavers through the match with the Carer. A detailed narrative is in Appendix 8.7:

**Figure 1: The Weavers program**



# 3.4 Administrative and demographic data

### 3.4.1 Weavers program survey data

Demographic data was provided for 26 respondents in the surveys. None of the respondents were Aboriginal or Torres Strait Islander, all 26 spoke English as their first language and all but one (n=25) were female. Respondents' ages ranged from 47 to 80 and the average age was 65.

**Table 3. Respondent ages (both surveys)**

| Age range | No. | % |
|---|---|---|
| 46-55 | 7 | 28.0% |
| 56-65 | 4 | 16.0% |
| 66-75 | 8 | 32.0% |
| 76+ | 6 | 24.0% |

The surveys highlight the difficulties being experienced by Carers, which led to their involvement in the Weavers program.

Eighteen of 23 (78.3%) respondents were caring for a partner, husband or wife with disabilities, three were children of the person they were caring for and two were 'other relatives'. Fourteen of 23 (60.9%) respondents were caring for someone with both physical and cognitive disabilities, six (26.1%) were caring for someone with a cognitive disability and three were caring for someone with a physical disability.

Data on the level of need of the cared-for person was provided by 21 respondents. Almost three quarters (n=15, 71.4%) were reported as 'high care'. There were also two respondents each who reported 'medium care', 'low care' and 'not yet assessed', respectively.

### 3.4.2 Data from the original version of the Weavers program survey

From this point forward the data is from only one survey. The survey which is no longer in use (Survey 1) will be discussed first, then the survey which replaced it (Survey 2) will be discussed in the next section.

In Survey 1, respondents were asked to provide information about themselves and their experience. Each question asked the respondents to answer in relation to the fortnight prior to completing the survey.

The first question asked respondents to indicate the number of times they had taken time to do something for themselves. Two respondents had not done so at all. Six had done so once or twice. Two had taken time on three or four occasions and four had done so five or six times.

Respondents were then asked to complete a series of four questions using a five point scale ranging from 'very low' to 'high'. The responses are shown in the table below.

For two of these questions, stress levels and sense of isolation, lower scores would be considered more positive. For the other two, sense of optimism and confidence, higher scores are more positive.

**Table 4. Carer wellbeing**

| | Very low | Somewhat low | Moderate | Somewhat high | High |
|---|---|---|---|---|---|
| My stress levels over the past fortnight have generally been | | 1 | 7 | 3 | 3 |
| My sense of optimism for the future over the past fortnight has generally been | 1 | 5 | 6 | 2 | |
| My sense of isolation over the past fortnight has generally been | 2 | 4 | 6 | | 2 |
| My confidence to do the things I need to as a Carer over the past fortnight has generally been | | 1 | 8 | 3 | 2 |

## 3.4.3 Data from the current version of the Weavers program survey

The new survey (Survey 2) is divided into four sections. The first section asks for demographic data and is discussed above. Nine respondents provided pre-program data.

The second section is the Carer Experience Scale and consists of six questions, each of which use a three point scale where '1' is the most positive and '3' is the least positive.

The table below shows the frequencies for each response for the six questions.

**Table 5. Carer Experience Scale (CES)**

| | 1 | 2 | 3 |
|---|---|---|---|
| Activities outside of caring | | 5 | 4 |
| Support from family and friends | 1 | 5 | 3 |
| Assistance from organisations and the Government | | 7 | 2 |
| Fulfilment from caring | 2 | 4 | 3 |
| Control over the caring | 4 | 4 | 1 |
| Getting on with the person you care for | 6 | 3 | |

*These CES questions each have 3 options under the 6 headings noted in the table (with examples of what those things might be provided in brackets). For instance, for the first heading, the examples include: Socialising, physical activity and spending time on hobbies, leisure or study, and the wording of the 3-tiered question is: "You can do...of the other things you want to do outside caring", with the options to fill in the blanks being 'most', 'some' or 'few'.*

The third part of the survey is the Personal Wellbeing Index in which respondents are asked to rate their satisfaction with eight aspects of personal wellbeing on a scale of 0-10, where 0 indicates no satisfaction and 10 indicates complete satisfaction.

The low number of respondents (nine) and wider range of scale scores makes presenting frequencies less helpful. Instead table 6 shows the mean scores for each question.

**Table 6. Personal Wellbeing Index**

| | Mean |
|---|---|
| Thinking about your own life and personal circumstances, how satisfied are you with your life as a whole? | 4.4 |
| How satisfied are you with your standard of living? | 6.3 |
| How satisfied are you with your health? | 5.7 |
| How satisfied are you with what you are achieving in life? | 5.0 |
| How satisfied are you with your personal relationships? | 6.4 |
| How satisfied are you with how safe you feel? | 7.2 |
| How satisfied are you with feeling part of your community? | 4.4 |
| How satisfied are you with your future security? | 6.2 |

The final section of the survey asks about health care service utilisation. Respondents are asked to answer yes or no to whether they have used any of five different services and, if so, how many times they used each one. The table below shows the number of respondents who reported they had used that service. The majority of respondents who indicated they had used a service did not provide data about how many times they had used it. It is therefore not viable to present those results.

**Table 7. Health service utilisation**

| | Yes |
|---|---|
| Routine medical examination | 6 |
| Dental examination and cleaning | 4 |
| Blood pressure check | 5 |
| Cholesterol check | 5 |
| Screening (e.g. skin check, pap smear, breast screen) | 3 |

With only four respondents to the post program version of the survey, analysis of post-program data for Survey 2 is not presented here.

### 3.4.4 Summary of survey data

The survey data shows that around three-quarters of Carers were caring for a partner and that a similar proportion reported the cared-for person has 'high care' needs. Almost half of the survey respondents report high levels of stress, low optimism and feel a sense of isolation. Few respondents selected the most positive category on any of the sections in the three-point Carer Experience Scale, except for 'getting on with the person you care for'. Scores on the Personal Wellbeing Index were in the mid-range (between 4 and 6 on average) on a 10-point scale.

# 4 Recruitment and engagement

## 4.1 Introduction

The main questions to be addressed in this section are focused on Recruitment strategies, Promoters, Carers and the future of the Weavers programme.

Answers to these questions will help to ascertain how viable and beneficial this program could be for the future and ways to improve it to enable growth and scale and to best help meet the needs of Carers and address gaps in the aged care sector.

# 4.2 **Data and findings**

## 4.2.1 Recruitment strategies: How has the program gone about recruiting Carers/Weavers and which strategies have demonstrated the most success?

### 4.2.1.1 TACSI staff interview findings

Recruitment strategies were not fully developed upon commencement of the project and evolved as the project progressed

> *"In the prototype the whole question of recruitment hadn't been fully resolved so we were still learning… learning about what method and what works to make that connection and I think we have a stronger idea about that now" (TACSI staff member)*

Similarly, it was necessary to identify who would be responsible for recruitment. The Local Connector acknowledged recruitment of Carers and Weavers and 'keeping the numbers up' as a significant part of her role, involving:

> *"…contacting and recruiting Carers , networking with organisations that are already connected to Carers, for having a referral pathway… community events where we will engage with Carers." (Local Connector)*

Strategies that did not sufficiently generate interest have been discarded and new approaches repeated if successful after a trial. The Local Connector described this change in her interview:

> *"we have combined two approaches: we've networked really well with an organisation…and then we hold an event on the back of that…" (Local Connector)*

The Local Connector intends to continue to support the strategies that have started to generate interest, including the 'High Tea' idea:

> *"We've become more aware of how we can connect with Carers… so we came up with the idea of holding a 'High Tea' event, for instance, and actually doing something really nice for people helped us to engage with them…so we're more aware of ways we can be creative in that space." (Local Connector)*

The Local Connector was asked about how the program started in Northern Adelaide and the reasons there may have been low numbers at that period of the program, and she proposed that:

> *"We're not offering a service, we're offering something completely different that sits alongside services that are already in someone's life. You definitely gain more by having the absolute support of the organisations that are connecting you to Carers… I think it's because services are so busy in delivering, if we're not at the forefront of people's mind they're not necessarily going to refer to us, but if we ring them and touch base, then they really appreciate the approach and the offer of a lunch and we got a lot of referrals on the back of those events as well." (Local Connector)*

The other TACSI staff member interviewed who had been involved in the early stages of the program noted that the initial focus exclusively in the north put unnecessary limitations on the establishment of the program:

> *"the provider of Carers Support is very, very active in the northern region…it took time to demonstrate the extra value we could offer…[the] combination of opening up to more networks and more regions and having a person really focused on the Local Connector role is…where some of the shifts came." (TACSI staff member)*

The extension of the geographic area, which TACSI affected around the end of 2014, was considered important in addressing recruitment issues. Also important was the shift of the role of staff involved in the program. For the establishment phase of the program, the original plan was for one staff member to have the Local Connector role, but this did not happen in practice. Many broader strategic needs were required in the establishment phase, such as identifying the learnings from the prototype, redesigning the model, recruiting Weavers, and securing funding. Once this had occurred, the Local Connector was freed up to focus on implementation.

Other factors that may have created difficulties for generating interest in the program by Promoters, as noted by the TACSI staff member in their interview, was the situation in the aged care sector at the time the Weavers demonstration program commenced:

> *"It's been hard for TACSI to try to help people understand that we're not about competing, we're not about being a service deliverer we're trying to show other ways that you can deliver services that truly meet the needs of what people really want... our path is to find where that sits in all the context of this reform"...(TACSI staff member)*

The Local Connector reported about recruitment and the main difficulty throughout 2015:

> *"We've always struggled to find Weavers...there have been quite a few potential Weavers [but after a] mutual discussion [early on] it is clear from their caring journey that they're not quite ready [and] quite often it is the Carer themselves who will identify that they are too close to their situation and still too wrapped up in their situation [although] in time they could be [ready]. I'd like to see a time where we can create something that could hold them in that space where they're still interested, but it's not right now, so we don't lose that connection...There is a Carer that was in a match two years ago who is interested in becoming a Weaver [and we are hopeful they will start to cycle through]." (Local Connector)*

Weavers must be selected carefully to ensure the success of the program. Balancing these requirements and engaging them in the orientation training, while trying to ensure adequate numbers are met, is an ongoing challenge for the program. The Local Connector, however, is hopeful that as time goes on, this may prove easier, if participating Carers reach a point at which they can shift into the role.

Sharing stories of success is a potential way to increase engagement and interest from Promoters, and so more engagement with existing Promoters through sharing stories would help, but the difficulty is balancing this while not breaking confidentiality for particular Carers' stories. This could be further explored. The Local Connector indicated that, in the immediate future, focus their efforts on targeted events for recruiting Carers, except where the demographic is very likely to generate interest from the relevant target group. The Local Connector is constantly working on building relationships with Promoters and looking for new opportunities.

During 2015, a major difficulty arising from the limited number of Weavers was recruiting Carers when there were insufficient Weavers with whom to match them. The usual process during this period was to explain the situation to Carers and try to give an indication of how long the wait might be (based on how long matches have been ongoing, and when they were likely to finish, on the assumption that matches lasted around 15 weeks). To address this issue, TACSI explored ways to make recruiting Weavers easier. In early 2016 the Local Connector reported, upon provision of the data, that this was no longer considered to be a constraint on Weaver numbers (see Section 4.2.1.3 below for more information). The Local Connector identified that the cohort of 12 Weavers as a March 2016 can service referrals within a month of referral.

What TACSI did to manage this issue through 2015, however, was that in the circumstances where Carers were 'on hold', the Local Connector kept in contact with the Carer, and sometimes they reached a point where they no longer needed a Weaver. The Local Connector sometimes provided direct support to these people (refer again to Section 4.2.1.3 for data), which might have involved pointing them in the right direction, for example, explaining how the 'My Aged Care' system worked or helping them to arrange for relevant assessments. The Local Connector reported that most of the Weavers who were with the program at the time of the interview had been involved with the program for around 3 years, suggesting that once Weavers were engaged they tended to remain engaged long-term. This could contribute to program continuity.

### 4.2.1.2 Weaver interview findings

Ten Weavers were interviewed as part of the evaluation. One Weaver noted in their interview that a key issue was attracting enough Weavers. This particular Weaver has had an active involvement in planning "presentations on Weavers at places of work... and the challenges you face as you get older" which in the end didn't take place, although the Weaver noted that the process helped "me to gain a lot more insight into the ageing sector, so I've been able to gain out of it". The Local Connector noted when asked later about this, that the 'Weavers in the Workplace' recruitment concept did not occur because of TACSI's focus on other preferred recruitment strategies to reach the required numbers. Although the concept was not implemented, all of the materials designed as part of this and the training of Weaver facilitators were utilised in other ways. This particular Weaver had therefore gone on to use this knowledge and information to support other recruitment activities, such as with Carer groups. This program involved the Local Connector doing a presentation then introducing the Weaver, who tells them about the role. The Weaver reported about this that:

> *"people have asked me questions...and they've gone really well and they've been very successful in gaining, not new Weavers, but in gaining Carers... So they've been more successful than the original [workplace] program, would have been because you're targeting the audience." (Weaver 9)*

Another Weaver during their interview noted:

> *"Like TACSI is considering, I think there need to be little hubs of support in different organisations. When somebody's referred in, they can go to the Carer and respite people and they can go to a morning tea...I've thought about where referrals can come from – I've got friends in Meals on Wheels. They would see couples or people in own homes and they [the Meals on Wheels people] say we don't have time to talk to them. [The Weavers program may be] what they [these people in their homes] need, they're so grateful to have someone in the house. So it's actually getting to the people that really need it." (Weaver 3)*

One of the Weavers in the focus group noted the following:

> *"I find when talking about Weavers [here meaning Weavers as a program] that one of the challenging things is that it's a unique program. So you start to talk to someone about it and they make a whole heap of incorrect assumptions. So there doesn't seem yet, because it's unique, a shorthand way of getting across quite what Weavers is and how it works, and that applies both for the Carers who receive support and the Carers who become volunteer Weavers. Every word you say, like you say volunteer and they think, oh yes, every Tuesday at seven o'clock or you say support and they, "Oh, so that means..." Every word you use carries a whole load of baggage which doesn't apply to Weavers. So your explanation of what Weavers is has to include quite a lot of information about what it's not and how it's different from this and that and the other. So that makes it, to me, a challenging concept to sort of push out into the community... It's not going to be something that's going to catch on immediately. It's going to take time." (Weaver 6)*

This above quote suggests there may be either a promotions design issue or an issue in communicating to Weavers about how the program is to be explained/marketed, and what the program is. There are staff in TACSI skilled in the area of promotion design who could design messages that work so that Weavers and others can more successfully communicate about what the program is and address this issue.

One of the Weavers in the focus group noted that Weavers apply some form of 'self-selection' in their engagement with the program:

> *"...my feeling is that there's a high degree of self-selection [of Weavers] because having gone out to some of these events where we chat to people, members of the public, "So you've done some caring, have you," and whatever and a lot of them will say, "I did it. It was horrible and I never want to have anything to do with it ever again." Well, they do. They say, "No, I do not want to think about it, I do not want to talk about it and no matter how much help somebody needs they're not getting it from me because I've put that behind me." So when you're talking about Carers who are either still caring, in a caring role, or who have moved on from it who are willing to maintain a presence in that - what would you call it - in that arena I guess...Yes, the self-selection, the willingness to keep, to maintain a participation in that whole business of being a Carer, that's very self-selective." (Weaver 6)*

This highlights that Weavers or potential Weavers may be a particularly specific group because past Carers often don't want to 'revisit' caring, which may limit recruitment of Weavers. This suggests that there may be specific reasons Carers invest in becoming Weavers, which supports the observation of the evaluator though the interviews that a notable proportion of active Weavers were Carers with either an aged care or other caring/helping profession background.

Among the 12 Weavers active in March 2016, TACSI confirmed that 3 have a work background in aged care, and an additional two have nursing or psychology backgrounds, suggesting that those with helping profession backgrounds are better represented among Weavers than they would be in the general community. The entire health and community services industry (of which aged care is a proportion) is 12.5% of the general population[7] and so you would expect a similar proportion among Carers. However, among interviewed Weavers it is five out of 12 (approximately 40%). This suggests that 'Carers with helping professions experience' is a group likely to be attracted to being a Weaver, which is therefore likely to be a relevant contextual element of the program theory. This could potentially be maximised or built upon in future attempts to recruit Weavers; perhaps effort could be directed to identifying the means by which such individuals may best be accessed.

For the Weavers who are not in the caring/helping professions, at least four more Weavers come from other professional/'white collar' jobs or backgrounds and additional clues may be found in the analysis of Weaver outcomes as to what other factors might motivate Carers to become Weavers (refer to Section 6.2.5), which could benefit future recruitment.

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[7] http://www.agedcommunity.asn.au/providers/workforce/ accessed 9 March 2016

### 4.2.1.3 Carer interview findings

The sources of referral for the 13 Carers interviewed in this evaluation were:

**Table 8. Referral sources to the Weavers program**

| Source of information/referral | No. |
|---|---|
| Carers organisation | 3 |
| Community centre/Council | 3 |
| Hospital | 2 |
| GP | 1 |
| Someone linked to a Carers organisation | 1 |
| A friend in a community group | 1 |
| Other community event | 1 |
| Can't remember/don't know | 1 |

The majority were referred by a Carers organisation, Community Centre/Council or Hospital. As most of these Carers were those who had engaged in the early stages of the program, the analysis of referral sources for those who are currently active in the program shows a different distribution (refer to section 4.2.1.4). This analysis of referral sources over time can highlight the types of organisations which have been the most successful sources of referral for further targeting, and also identify any shifts in referral sources arising from the newer recruitment strategies.

### 4.2.1.4 Local Connector/Weavers program data

For 2015, the Local Connector reported 16 enquiries for Carers considering the role of Weaver. Of these, four became Weavers, three withdrew, and two had an initial meeting at which it was identified they were not ready. Seven are still potentials on a waiting list for training. There has also been an additional person added to the waiting list in 2016.

In terms of the current status of Weavers in March 2016 (refer to Table 9), 12 were active (including two from the prototype phase and two new ones in 2016). A thirteenth Weaver withdrew prior to starting a match. Of the active Weavers, the majority (five) have completed two matches, while at either extreme, one has completed four matches and three have not completed any. This total matches with the number of completed Carers that were interviewed (13). The Local Connector reported that in March 2016 remain three to four potential Weavers in waiting.

**Table 9: Status of Weavers**

| Number of Weavers | Number of completed matches | Number of ongoing matches |
|---|---|---|
| 1 | 4 | 5 |
| 2 | 3 | 2 |
| 5 | 2 | |
| 1 | 1 | |
| 3 | 0 | |
| Total 12 | 13 | 9 |

In terms of ongoing matches at the time the data was provided in March 2016, a further nine matches were active into 2016 (and one match was pending). Four of the Weavers were not in an active match at the time (although two of these are new and one of these has a pending match).

**Figure 2: Referral source**

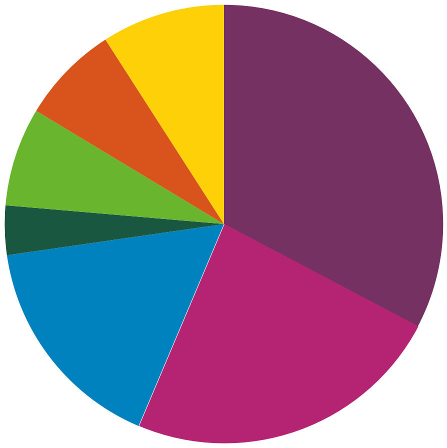


**Figure 3: Matches as at March 2016**

Figure 2 shows that around one-third of the 53 Carers who were initially referred to Weavers were referred through a recruitment event. The other two main sources were the Social Worker at Flinders Medical Centre and Carer Support Services.

Figure 3 records the status of Carer matches from the referrals. The number of Carers in the figure adds up to 55, two more than the above because: one was pending and then withdrew so was counted in both categories; another referral from Flinders Medical Centre didn't result in any contact.

Through 2015 there were nine occasions where the engagement with the Weavers program was through Local Connector only. Three of these were interviewed as Carers who had opted out of the program. The reasons for the Local Connector being the only contact were that:

- Their needs were suitably identified at the first meeting and the Carer was able to proceed for themselves;
- Their caring situation changed;
- Three Carers required more extensive support from the Local Connector as it was found that theirs need were more complex and the Local Connector was able to provide other service options and contacts for the Carer.

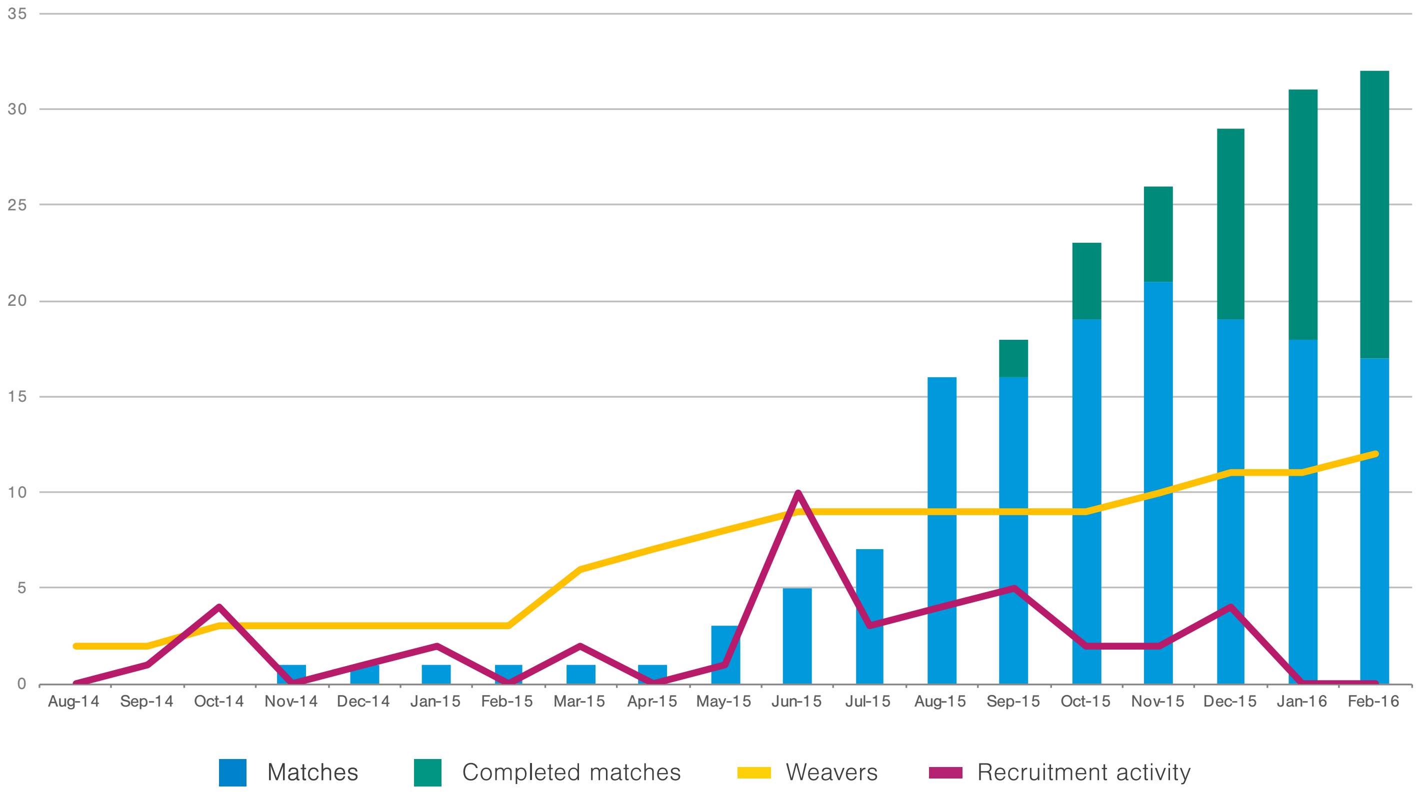
Approximately two-thirds of Carers (35 of the 53) referred to the program progressed to a match with a Weaver – Carers 'recruited' see Table 8 below). Thirty-two by March 2016 had started a match and 15 had completed (approximately 28% of those referred) a match.

**Table 10: Carers who progressed to a match by March 2016**

| Year | Carers recruited | Carers started a match | Carers ended a match |
|---|---|---|---|
| 2014 | 3 | 1 | 0 |
| 2015 Q1 | 0 | 0 | 0 |
| 2015 Q2 | 5 | 4 | 0 |
| 2015 Q3 | 17 | 13 | 2 |
| 2015 Q4 | 6 | 11 | 8 |
| 2016 | 4 | 3 | 5 |
| **Total** | **35** | **32** | **15** |

Figure 4 below shows a notable increase in recruitment levels from August 2015. This is likely to be due to a combination of the additional resources available for recruiting activities within the program at the same time as a shift in the focus of such activities (noted in section 4.2.1.1). Specifically, the Local Connector had become full time from March 2015 and TACSI provided an additional resource to specifically support recruitment activities in the Weavers program from April 2015.

**Figure 4: Recruitment data**

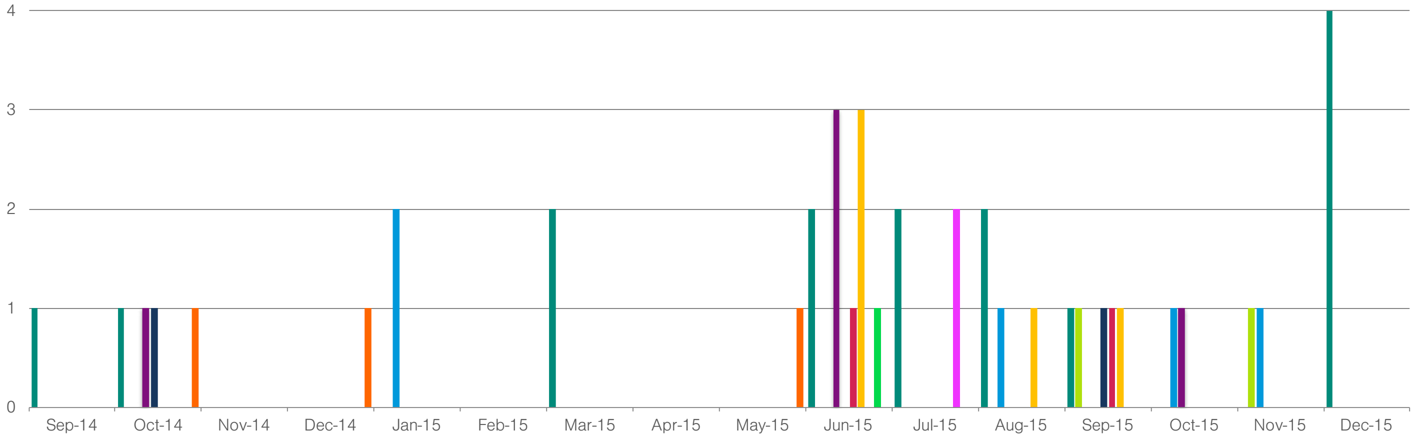


| | Aug-14 | Sep-14 | Oct-14 | Nov-14 | Dec-14 | Jan-15 | Feb-15 | Mar-15 | Apr-15 | May-15 | Jun-15 | Jul-15 | Aug-15 | Sep-15 | Oct-15 | Nov-15 | Dec-15 | Jan-16 | Feb-16 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Completed Matches** | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 4 | 5 | 10 | 13 | 15 |
| **Matches** | 0 | 0 | 0 | 1 | 1 | 1 | 1 | 1 | 1 | 3 | 5 | 7 | 16 | 16 | 19 | 21 | 19 | 18 | 17 |
| **Weavers** | 2 | 2 | 3 | 3 | 3 | 3 | 3 | 6 | 7 | 8 | 9 | 9 | 9 | 9 | 9 | 10 | 11 | 11 | 12 |
| **Recruitment Activity** | 0 | 1 | 4 | 0 | 1 | 2 | 0 | 2 | 0 | 1 | 10 | 3 | 4 | 5 | 2 | 2 | 4 | 0 | 0 |

Figure 5 shows how the above factors led to a notable increase in recruitment activities from May 2015, and specifically increased liaison/networking with:

- Community groups (5 held June to September; 3 of these in June; none in the 9 months prior to this)
- Support groups (4 held June-October 2015, 3 of these in June; only 1 had been held in the previous 9 months)
- Service providers lunch (2 were held in July, just prior to the increased activity and none had been held prior to this) coinciding with increased intensity of meetings with service providers (6 in the 3 months of May to July 2015, while only 4 had been held in the prior 9 months)
- High Teas held in September and November for the first time – increases continued to occur through these months.

**Figure 5: Recruitment activity**



| | | Sep-14 | Oct-14 | Nov-14 | Dec-14 | Jan-15 | Feb-15 | Mar-15 | Apr-15 | May-15 | Jun-15 | Jul-15 | Aug-15 | Sep-15 | Oct-15 | Nov-15 | Dec-15 |
|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|---|
| **Meeting with Service Providers** | 🟩 | 1 | 1 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 2 | 2 | 2 | 1 | 0 | 0 | 4 |
| **High Tea** | 🟩 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 0 |
| **Community Event** | 🟦 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 1 | 1 | 0 |
| **Support Group** | 🟪 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 0 | 0 | 0 | 1 | 0 | 0 |
| **Expo** | 🟦 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 |
| **Networking Event** | 🟥 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 1 | 0 | 0 | 0 |
| **Community Group** | 🟨 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 3 | 0 | 1 | 1 | 0 | 0 | 0 |
| **Services Lunch** | 🟪 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 2 | 0 | 0 | 0 | 0 | 0 |
| **Workshop** | 🟩 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 |
| **Public Recruitment** | 🟧 | 0 | 1 | 0 | 1 | 0 | 0 | 0 | 0 | 1 | 0 | 0 | 0 | 0 | 0 | 0 | 0 |

### Recruitment Strategy for Weavers

There were three major iterations in the recruitment strategy for Weavers during 2015.

1. More emphasis and time spent in cultivating strong relationships with key service providers who had shown a keen interest in the Weavers model of supporting carers. This was done through the Local Connector maintaining regular contact and creating opportunities to hold discussions with managers and link workers who had direct involvement with carers and care recipients. Where the service provider showed a keen interest in Weavers a request would be made to host an event for carers at an appropriate setting relevant to the aged care facility/support organization. Some of the most effective results where when the service provider made direct invitation to carers who used the facility.
2. Increasing the opportunities to engage with carers through hosting special events to create an atmosphere of being ‘cared for’ such as a High Tea or a Services Lunch. We found that through creating an event where we were able to give back in some way to the carers or the service providers the conversations that resulted were more relaxed and open to what Weavers could offer.
3. A very powerful strategy was to involve the Weavers in the recruitment events so that conversations held with carers were at a very genuine and empathetic level as the Weavers have ‘been there and done it’ as a carer themselves. The fact that a Weaver can share their personal story at a public event enabled carers to hear what Weavers was about in a very different way and was often lead to a carer making a personal referral.

In respect to the targets for recruitment noted in section 2.1 – the revised targets being 15 Weavers and 60 Carers – the demonstration project has fallen a little short at 12 Weavers and only a little over half of the proposed numbers of Carers (35 progressed to a match. The number of matches per Weaver is higher than predicted compared to the original program design of one-to-one.

Any organisations implementing the learning from this program should be mindful of the difficulties with Carer and Weaver recruitment. Significant resources were needed to generate referrals and engagement in the program and so cost-benefit should be a consideration in future models. It is possible that once the program develops credibility with service providers or engages more directly with them, recruitment may not prove to be so resource intensive and may prove to be more cost-efficient over the long-term.

### 4.2.2 Which Promoters refer and why? Of those approached to become 'Promoters' of the Weavers program, who does and does not become a referral point and why/why not?

The five Promoters who were interviewed and have referred to the program found it a positive experience, were pleased with the outcomes, and would be likely to refer again. A couple indicated they would appreciate additional feedback from TACSI about how the match went. One of these says:

> *"The thing I really like about Weavers is that it fills a gap...We acknowledge the strength you have and support you in doing that. I know that all of the people I have referred, that people are delighted. It's building on the strengths and what's working and solution focused stuff...Whereas most Carers support is based pragmatically on the deficit model ...." (Promoter 2)*

For the five Promoters who had not referred to the program at the time of interview, there were a number of constraints to referral. The first was the Promoters' belief that their or another's service adequately met the needs of Carers with whom they were in contact, including those who wanted to connect with/help other Carers (through support groups). This raises the question of whether there is a sufficient market for this program, given there are already a number of other services in the market to address Carers' needs. Factors such as market segmentation (how, when and where this service might meet Carers' needs, beyond or in competition with similar services), and whether its point of difference over other services outweighs the cost of providing an additional service where there are already services engaged, would need to be further explored in any continuance or expansion of the program. Whether this was simply a perception issue that should or could be overcome is open to debate.

The second concern for Promoters was their reservations about the capacity of Weavers to meet the needs of Carers. Three of the five potential promoters identified this as a concern. They were particularly concerned about how Weavers might deal with boundary issues and their knowledge of relevant up-to-date information, supports and services to help Carers navigate the system. One Promoter who is quite clear on what they see as the strengths of the program still has reservations about placing their Carers in the care of a Weaver:

> *"The strengths [of the Weavers program] are obviously that it's utilising real life experience that people have had, so straight away you forge a connection with the client – with the people that you're working with. I think the strength of the program is the training model, and I think that aspect of narrative and telling stories is really valid and very powerful. The weaknesses of the program are always going to come down I think to who's recruited and how they actually exercise their role and keep boundaries appropriate, to what extent they refer on where they see the need...one of the things I was a bit cautious about you know, ... I feel somewhat protective of people that are Carers already.....I think that has to be very skilfully monitored. That you're not putting the Weaver in a vulnerable position... ...there needs to be some caution there. And I think it's the same issue in any volunteer program in being really clear about why somebody is wanting to be a volunteer because sometimes it can be addressing a neediness of their own and then it's sometimes not the most healthy relationship or then people do blur the boundaries of what's appropriate and what's not." (Promoter 10)*

While this respondent obviously has a good understanding of the program model, the feedback suggests that the Weavers program could benefit from increasing awareness among potential Promoters of the process and criteria for recruitment and engagement as a Weaver, where the boundaries lie, how they learn about their boundaries, and how such boundary issues are monitored and managed. In relation to recruitment of Weavers, the above Promoter also noted:

> *"it would be interesting to talk with some of the people who had the information and what their barriers are to becoming involved. I think it sometimes is about - at what point do you take on a role like this? You need to be in a fairly together position to be able to offer that sort of support to somebody else and to do it in a way that's an ongoing commitment." (Promoter 10)*

A third reason Promoters did not refer to Weavers was because of a preference for referral to a more 'mainstream'/centralised referral point first. Where this is the case, ensuring Weavers is one of the options promoted by such services could help to increase rates of referral. One quote explains the reasoning behind this:

> *"I tend to think of Carers SA as being the overarching organisation which will then refer people to all the different kinds of Carers support. So they will refer people on to support groups, to counselling, to respite, to whatever they might need and I would think of Weavers [the Weavers program] as being one of those – that mentoring program as being one of those things. Rather than, if you refer people on, you don't want to give them lots of different numbers, so if possible you want to give them one point, so I would refer them to Carers SA first off." (Promoter 5)*

For one of these five Promoters who had not yet referred, the main reason was due to restructuring and changes within the organisation, which meant that staff systems and practices were not sufficiently established to raise awareness of the program and to set up a referral process, but they hoped to be able to refer to the program in the future.

Two of the five Promoters who have referred had originally had doubts about the program or the Weavers' role/capacity, but they have both been very satisfied with the feedback they have received from Carers and have since become strong advocates of the program. They either have or will continue to refer to the program.

Among Promoters there was inconsistent understanding of referral criteria for the program. A few noted the (age) criterion (where they were aware of it) was a constraint to further referral: it meant that the program could not become part of a standard approach to Carers. One notes:

> *"Because of the criteria it's a little bit limited because we get so many patients with such wide and varied illnesses that their criteria does limit us quite a bit but as soon as we get anyone in that fits the criteria I'm the first one to refer..." (Promoter 4)*

A few of the promoters thought the Weavers model would work well if the criteria were broadened, for instance for Carers of younger people who may lack access to appropriate services or perhaps those with Asperger's/Autism spectrum disorders. A couple of the potential promoters proposed that meeting niche needs like these that are not as well served by other services may increase referrals.

Most promoters/potential promoters interviewed seemed to support the idea that, to reach an adequate level of referrals, the Weavers program will need to link better with mainstream services, for example, develop closer working relationships or partnerships. One promoter proposed using promoters/key people in the sector to 'champion' the program.

Many promoters believe that the Weavers program, as a less 'mainstream' service, not limited by geographical and other boundaries, has the potential to fill the following types of gaps in the system:

- geographical (where there are no/limited other peer supports);
- service (become specialised/'disease'-specific, by recruiting Carers who have cared for people with particular diseases and who develop expertise in that area and support similar Carers);
- need (Carers for whom 'mainstream' group/professional services don't appeal or who are isolated or home-bound).

One Promoter discusses how, for instance, regional areas may be an area of need:

> *"I see that a program like this could be of use to particularly isolated people. I think it could be really valuable, particularly in regional areas, where there's not a lot…[where] we're not able to provide through our resources, a lot of support. So it's a model I think would work well in a regional area." (Promoter 10)*

As noted above, a few Promoters identified gaps around need, and proposed that the Weavers program might gain some traction where particular Carers or groups of Carers have proved 'hard to reach/engage' in existing mainstream groups and services. One suggests:

> *"There's a large number of people in the community in the North Eastern region who don't seem to access services anywhere near to the same extent as people…here…People in the north east either go off to the Port to access services or…all the way to the north or all the way out to Tea Tree Gully or eastern suburbs but in that region there's not a lot of services based there….There is an area there, yes [of opportunity]." (Promoter 1)*

One of the Promoters who had referred to the program was convinced that the program especially appealed to those that didn't tend to fit mainstream services:

> *"…even with this system of flexibility they [can't always provide] what the Carer needs. It normally is either somebody who is not mainstream…people who don't fit…the [other] services…" (Promoter 2)*

Promoters suggested Weavers program staff should continue to liaise with, and expand/increase liaison with, organisations and professionals in the aged care/Carer sector, including holding service provider networking lunches (this event received very positive feedback, especially as a means to better understand the Weavers' role and capacity). It was also suggested the program should capitalise on some of the upcoming changes in these sectors, such as centralised referral/contact processes (while maintaining the Weavers program's flexible approach and low key referral style as much as possible).

A few Promoters proposed the Weavers program could get in earlier, to capture those not yet linked to Carer services, by connecting directly with GPs, Centrelink (for Carer payments), churches, and pharmacies.

A couple proposed that hospitals could also provide a particular opportunity, because often when Carers present to hospital, they are experiencing crisis or not coping and so are potentially more open to services. As well, hospitals are placing increasing priority on responding to Carers due to their inclusion in accreditation processes and the focus of Transforming Health on preventing 'rebounders' in the system. As noted previously, a good proportion of referrals into the program have come from one particular major hospital, but this suggests that the program could perhaps benefit from targeting additional hospitals.

The above information was reported to TACSI as part of the evaluation's interim report in November 2015 and the findings may have informed the program's progress since that time (see also Section 4.2.4).

## 4.2.3 Which Carers engage and why? What are the reasons Carers might not engage the program?

### 4.2.3.1 Carers who opted out interview findings

All Carers who decided not to engage in the program did so prior to meeting their Weaver. There were two reasons the 6 Carers interviewed (one male, five female) gave for this:

- External circumstances (such as the person being cared for dying or being moved into an aged care home, or a 'falling out' in the relationship) – 3 Carers
- Sufficient satisfaction with their current situation and/or seeing no need for a further service (sufficient access to other support services, just too busy and/or not enough of a need that they have pursued it) – 3 Carers

All of the Carers interviewed who 'opted out' described their experience of the program as very positive. Two suggested that if circumstances changed, they might seek out the Weavers program for support. Their suggestions for improvement included broadening access to the program (making it available interstate) and updating the website.

### 4.2.3.2 Carers who completed interview findings

Some insight into why Carers did engage with the program can be gained from interviews with Carers who completed a match. Five Carers specifically noted how the program provided a point of difference compared to other services, such as access and flexibility, which attracted them to the program.

One Carer referred to this flexibility:

> *"Actually yours was the only [service] I've had until only recently and…I've been trying for help [for months]…Yours was the only one that offered this kind of service, coming into the house, even just talking…I was going…once a month to a group of Carers but it got a bit difficult for me…I can't fit it in, I get busy here…and I don't drive…we haven't got a car anymore…I have a walker as well you see so it's hard on the bus." (Carer 3)*

This example highlights that although providing respite for the Carer by looking after the person being cared for is not the intent of the program, the Weavers by the nature of the close relationship they develop with the Carer and the nature of the program, will sometimes adapt and respond to specific requests of support. The pros and cons of this aspect of the nature of the relationship may need to be considered further, as other services are both intended for and better equipped for this.

Another Carer noted:

> *"[I told my brother who's interstate] If I didn't have [the Weaver] I don't know where the hell I'd be right now, probably in the room with my mother [the person being cared for, who is in a home]. If I wanted to ring [the Weaver] now I could, and if she couldn't answer, she would ring me back [whereas others, like my family, wouldn't necessarily be able to]…Because I don't have many friends, I will ring her and she will be there. Even going to the Carers organisation is "not the same" – this is more direct and more real, although that's perhaps not fair to that organisation, but with [the Weaver] I never know what she's going to say, and that's good but at least I know she's on my side and will support me and knows what I'm going through." (Carer 9)*

Weavers seemed to meet the needs of these Carers promptly and well, as another states:

> *"I think one was Weavers [as a program] stood alone compared to all the other organisations. I was told about [one Carer organisation] and they just wanted to know about [the person being cared for's] needs and sent pamphlets on incontinence and that wasn't what I needed at the time. And the same with [another Carers organisation]…They were the only two organisations I knew about anyway. Both didn't seem to help at all." (Carer 2)*

Regular contact and follow up was valued as well by one particular Carer:

> *"I guess in a way, I haven't really used that many services – we're registered with [a Carers organisation] and respite, but don't have regular support from them. I guess the…regular contact is good whereas you don't always get that from other places just you get put on their books and just sort of forgotten about or you might get a newsletter sent out but unless you ring up and specifically ask for some help with something then there's not that regular contact, 'How are things going?…Is there anything you want to talk about?' So I found that very good…the fairly regular contact [because it] just gave you a chance to chat with someone to go through any problems that you'd had since the last chat or anything that was happening at that time that you want to talk through or how to handle things. 'What could I do about that?' Just regular advice, someone to talk to, someone to offload on." (Carer 8)*

The flexibility of the Weavers program was a key factor that helped to attract Carers, as one Carer points out:

> *"It also highlighted the deficiency which I was already aware of, that [a particular caring organisation] doesn't cater for people who are… working…a lot of their services are during the day which obviously I can't access." (Carer 1)*

### 4.2.4 How should the Weavers program position itself for the future? What roles does this program play in the current aged care sector and where should it best position itself to best meet the needs of the Carers?

Through the Weaver interviews, Weavers highlighted that their knowledge and experience should continue to be used to further engage with Promoters and potential Carers to promote referrals. They also sought to highlight the key point of difference of the program: one-on-one engagement with someone who has been a Carer themselves. One Weaver notes:

> *"We've all been through this experience before, we know what it's like to be a Carer and understand their needs and that's a really good point when we're talking to them...The Local Connector says: You're the Carers, you know more [than us]. So that's a really good point of difference...Some of the Carers have been in Carers groups, but some need one to one – in groups, some of it isn't appropriate, most people won't open up to that extent when they're in a Carers group. [I'm] not aware of any other that does one on one with Carers except perhaps professional counselling services." (Weaver 3)*

The TACSI staff member noted that this type of program, based on her interviews with service providers, fills a gap in the aged care system:

> *"The main model tends to be phone counselling and peer groups and then individualised support by paid workers so it really does seem to fill a gap in what others are able to provide to Carers and they know that one-to-one support is really critical..." (TACSI staff member)*

The Local Connector noted in her interview that shifts are already beginning to occur to develop a future direction, based on the interim findings of the evaluation and the learnings that TACSI has gained from the program to date:

> *"...we're looking at putting ourselves alongside another organisation and those conversations have already taken place...TACSI's not a service provider,. ...What would be a good thing to have now is to do a quite detailed document ourselves of what has worked well and so once the reports are done... then have the Weavers work with us to work on the model, what do we keep...what do we not keep, what do we adapt?...[With the aged care service we're talking to] we'll take what we can learn from Weavers and co-design what is appropriate for their particular organisation. I don't think there's any expectation that they'll take Weavers on as is, but there'll be core things that have worked well..." (Local Connector)*

The Local Connector suggested that the Weavers program is unique in its adaptive change model and narrative practice approach with a specific focus on taking the individual Carer from the place where they feel out of control to a place where they can make decisions. This was seen to be a 'core element' of the program that should be retained in any future redesign.

A Weaver highlighted their concern about longer term funding:

> *"They've obviously been given a certain amount of funds to run the Weavers and I wonder how long that will last...I have concerns about how it will exist in the long term." (Weaver 8)*

The evaluation terms of reference did not include cost-effectiveness and the evaluators do not have any budget information to determine cost-effectiveness. Consequently, no assessment of this has been made in this evaluation. TACSI, however, has indicated that they will be mindful of cost to client ratio in future directions for the program. As they have done for their other programs, they intend to conduct an internal cost-benefit analysis. They are also mindful in their discussions with possible future partners that the model may need to be adapted to increase its cost-effectiveness. A range of options are being considered, such as fee for service and involving private health providers in supporting the program as it may be of benefit in terms of health and wellbeing to some of their customers which could reduce longer-term health costs if successful.

The TACSI staff member noted about the future of the program:

> *"We've learnt a lot, we know what's core, about principles and methodologies that are scale-able and we're naming those core things and we're out interviewing Directors and CEOs about the value they see Weavers providing their customers as Carers and them as an organisation and what their views are about [possible] revenue spaces...if Weavers were available to them, what would they need...thinking about setting up a social business that's focused on the spread of Weavers...continue to innovate and grow the possibilities...also having those conversations with Weavers themselves... how do they feel about their expectations...and those accessing Weavers too...in research phase about the business model...then social enterprise... investigate what sort of seed funding...could be dedicated to that mission..." (TACSI staff member)*

This staff member also noted that low recruitment numbers would be an issue for a service deliverer but that the purpose of the demonstration program and TACSI's approach to issues is more about identifying successful core principles and learnings to take forward that will assist in defining a workable model to address Carer wellbeing. The aged care organisations that she has been interviewing with often use volunteers, but they are not necessarily fully used as a resource. Weavers and organisations could therefore benefit from better engaging existing Carer volunteers within the sector. TACSI has also had enquiries from other fields such as palliative care and other Carer support groups, because it is focused on the core needs of Carers, and many providers and others can see the synergies between this program and what they are trying to do to support Carers. These enquiries could provide real possibilities for the program.

# 4.3 Summary and conclusions

The Local Connector has worked on new strategies to increase referrals of Carers which have showed some promise. For Promoters, these include building on established relationships with them by inviting them to follow up events (service provider lunches) that includes meeting Weavers. For Carers, this involves focusing on events that are more likely to attract the target group of Carers (such as a 'High Tea'). However, the numbers continue to remain lower than expectations (a target of 60): 53 Carers were referred to the program, 35 progressed to a match and 15 completed the program.

Promoters who refer to the program are happy with it. Two of these five Promoters originally had doubts about the program, but once they had an experience with the program they became advocates for the program, suggesting it is possible that reservations of service providers may be overcome. Promoters that had not referred at the time of interview identified a number of issues. There are a number of issues with promotion of the program, as Promoters are not clear on the age criteria and what the program is and does. There are other concerns, such as the Weavers role, particularly the issue of how the program ensures through its selection, training and support processes that the Weavers' own caring experience does not cross 'boundaries' and impact on how they support other Carers. Some promoters believed that other services already sufficiently meet the need or that they would rather refer to a central referral point. A few also noted that the program does have the potential to reach and provide a service to a 'niche' market.

Those Carers who do engage in the program find its flexibility and responsiveness attractive. Those who do not engage usually do so because external circumstances prevent it or circumstances change and they no longer have a need for the support.

It has been a challenge for the program to recruit and engage Weavers and Carers. Throughout 2015 the low numbers of Weavers particularly constrained the program's growth. They are likely to be a very niche group of Carers as many Carers do not wish to re-visit their caring experience. Those who do may have very specific motivations for doing so, which may be able to be drawn upon to access them in the future (for instance, a work background in the aged care or other caring field). Finding them may prove easier as time goes on and previous participant Carers become Weavers or the program becomes more embedded in a Carer organisation). Promoters also note that the credibility of Weavers is essential to the success of the program and that engaging Weavers in promotion of the program may be beneficial.

The low numbers of Weavers made it difficult to manage Carers and in some cases the Local Connector provided support. When later approached, some Carers no longer needed the support. Carers who opted out often did so because of this reason or because external circumstances prevented it. Extra effort directed to recruitment of Weavers eventually led to some success and as of March 2016 there were 12 active Weavers in the program. This, however, is a few short of the target of 15 as identified by the CDPC.

TACSI has commenced working on future directions for the program, in discussion with service providers, Carers and others. Future work will consider the learnings from this demonstration program, particularly drawing on the learnings from what it took to increase recruitment and referral numbers, and consider factors such as cost-effectiveness in the business model design.

# 5 Support for Carers and Weavers

## 5.1 Introduction

This section reports on the support provided for Carers and Weavers, particularly to identify which of the supports and tools offered in the program were beneficial and which experienced difficulties or were not beneficial.

# 5.2 **Data and findings**

## 5.2.1 Local connector and TACSI support

Every Weaver spoke positively about the support provided by the Weavers program and specifically the role of the Local Connector. About half of the Weavers identified the flexibility of the program and TACSI's responsiveness through the Local Connector as a key factor in both their continued involvement in the program and the success of matches to date. TACSI were quick to address the needs identified by any Weaver and the Local Connector was able to adapta to whatever way suited the Weaver to make contact with her and provide feedback on the progress of matches, whether phone call or email. Two of the Weavers' comments are provided below:

> *"Probably its leadership in the (Local Connector)... Without having somebody at the helm...at the top who is also confident and very articulate. She knows how to express herself and she knows how [to get] what it is that you're trying to convey to her.... is really, really patient with all of us, and always going that little bit further. She accommodates you, works around what's going on in your life, in order to help you out. It's not only I'm only free on this date and this time – she's very giving.." (Weaver 2)*

> *"Well what I can say is just my fear for the program in the long term...when [the program] goes to other organisations it should continue [as per TACSI's approach] to value every input, you know, the way they capture and respond to all the feedback. And they knew everybody's input on absolutely everything. That's something that would ideally be retained...a lot of the power of supporting and enabling Weavers to go out and do a good job at what they do comes from that. ...But that's something that because TACSI does it and they do it in an explicit way, then that coaches every Weaver to also do that and then when you got out to meet your Carer, again you're doing that. Everything they say, you're not overlooking things or deciding to focus on that thing because that's easier for you. You're capturing their experience and responding to the whole of that and respecting every aspect of it." (Weaver 6)*

The above quote discusses how TACSI's valuing of Weavers enables the Weavers to mirror this valuing in their relationship with a Carer. This is an important mechanism, a form of psychological mirroring, which should be considered in how the Weavers program functions. Three Weavers discuss the importance of its person-centred approach:

> *"...there was an opportunity to do another match up but I felt comfortable to say no. I have more confidence to be able to say what my limitations are because the focus of program is caring for yourself as well. That's been a bonus – remembering to look after yourself and that's great." (Weaver 4)*

> *"One thing – [Carers are] assessed really thoroughly to start with. (Local Connector)...teases out all the issues we need to work with them on. And that's really helpful just so we don't go in cold." (Weaver 3)*

> *"I think what I like about it: it's in aged care what we would call person-centred. .... but there's a person to connect with, and that makes the program quite unique and it's always the same person who is the contact rather than being an office full of people that you may not get the right person that knows your personal situation and your role and so that's a great advantage but also knowing they are supported by a team of people that will contribute to things like the Learning Lunches and web design etc. So there's a good team backing the coordinator." (Weaver)*

From the focus group the following benefit of the Local Connector role in setting the objectives of the match was noted:

> *"We turn up together. So yeah, there's an absolute bridge [you] turn up the first time and know that somebody who has already met them is going to be there. You just sort of - it's more relaxing and I think it does make Weavers [as a program] more accessible to a wider range of volunteers. But you don't have to have massive confidence in your ability to meet people and gauge quickly and so on to be a Weaver because there is that bridge between the contact with TACSI and sort of handing the person over to the Weavers." (Weaver 6)*

One area that could be managed better is the 'ending off' process. This has been identified as a key problem by Weavers and Carers alike through the interviews. A couple of Carers particularly noted that they were unclear in some circumstances as to whether they had completed their formal engagement in the program. Another suggested area for improvement noted by one Weaver was that they would have liked to have had more involvement in the evaluation process.

A few Weavers noted that all the support provided by TACSI to the Weavers constituted a 'package' of support, all of which proved useful in some way. Even if they didn't specifically apply it in their match, it informed their practice.

### 5.2.2 Orientation Training and Weaver Learning Lunches

The Orientation and the ongoing professional development via Weavers Learning Lunches (that sometimes included guest speakers), were consistently highlighted by all Weavers as important features of the program that worked well. The focus group noted that the training was responsive, client-oriented and involved very practical 'workshop' style elements. One Weaver through their interview noted that the guest speakers "give you an insight into different areas", such as what they do, and furthermore, "...it's good to hear other people asking questions about the services".

The Learning Lunches have provided a good opportunity for development with peers and a form of situated learning that builds up the community of practice for these Weavers. Specific comments about how this sharing with peers has helped is noted three Weavers below:

> *"I think it's just the backup that quite often at lunches we will say, 'Well, I did this...could anyone else have done it differently or do you think it should be done differently? And they could say, 'Well, the approach could have been this'. That's just another value of sharing and it's done in such a non-confrontational way that I think that's the value of...the way Weavers works." (Weaver 5)*

> *"Because everything is reflected upon and everyone is invited to reflect in the group situation on what they are doing as a Weaver and also to reflect back to other Weavers, what those other Weavers are doing. So we're constantly feeding off each other in terms of not just ideas and suggestions and so on, but worries and fears and all of that." (Weaver 6)*

> *"I think the most [useful thing is] probably the opportunity to have that one on one counselling, for me, in a way that's what (Local Connector) does for you. If you've got an issue with your Carer then you're able to talk it over with (Local Connector), or the other team members which is really good and we all help problem solve because that's part of our Learning Lunches: to review...the case studies and then problem solve as a group. So it's a case management approach..." (Weaver 4)*

In any team approach or group dynamic, with different personalities involved, there is always a risk that some individuals will experience difficulties with the dynamic. In the Weavers program to date, most Weavers highlight how well the group gets along (one noting they are 'like a little family') a couple of Weavers have noted that this is because the Local Connector has been perceptive enough to identify any potential situations and address these before they have become problematic.

Support tools that are provided through the Orientation and ongoing Learning Lunches are not necessarily consciously used by the Weavers with Carers in their match, although in a couple of cases they noted that it was a particularly useful tool for their own needs. Using tools formally in the match can seem a bit too structured or prescriptive and Weavers suggest this could potentially constrain the relationship. The Weavers prefer a more natural and fluid approach when working with their matched Carer. However, the focus group did note that having such tools is still beneficial because they don't have to use them, but they are useful as something to turn to if they find themselves unsure of what to do. The focus group also noted that these tools are useful to reflect back on to check that you are heading in the right direction, while still maintaining the flexibility of the program, which they believe is a major part of its appeal to Carers. One of the Weavers in the focus group noted that they had particularly drawn on narrative approaches, given how that helps with sharing stories.

One Weaver explains how what they have learnt becomes integrated in what they do:

> *"There was always a process that we got taught. But you see the reality is that when you're dealing with somebody in front of you they don't want to follow processes, because they've got their own line of...thinking and really...as a Weaver, you're guided by them because they know what they want. But to go in with a rigid format is not...conducive to them. They don't all fit the template but you use the template to grab stuff out of it when the need arises, on occasion, with the situation...Not always as simple as black and white...there're always lots of other variables involved...I've used some of them though, a book we've read, and that was quite interesting, and understanding about selective feedback..." (Weaver 2)*

Only three minor criticisms were noted by Weavers about the training and Learning Lunches. One Weaver through the focus group noted that sometimes the Learning Lunches don't run to the agenda, although they acknowledge that this is more about the Weavers talking too much and not necessarily TACSI's fault. Another Weaver in their interview noted that running overtime on the agenda could become a problem as the Weavers program continues to expand. One Weaver with an aged care background noted that sometimes the guest speakers would provide little in the way of new information/knowledge for them, but that this was not necessarily a problem as it still provided useful revision. Another noted that they had difficulty getting into the city and finding suitable parking for the Weaver lunches.

### 5.2.3 Loom and other support

Six Weavers (either through the focus group or via individual interviews) mentioned difficulty with the Loom (a web based tool for recording information about matches and shared communication) which is meant to be a support tool to help the Weavers communicate with the Local Connector and each other. Issues included: lack of compatibility with personal computers, problems with functionality, ongoing glitches, and a lack of capacity or aptitude for the Loom or computers in general. According to the focus group and the Local Connector, the Loom did at one point function adequately but while remodelling it, it seemed to have fallen out of use. Most instead maintained contact with the Local Connector via email or phone. Half of those who highlighted the difficulties with the Loom thought it could be a useful tool, if functioning.

### 5.2.4 Weaver support to Carers

When Carers were asked about specific types of support provided to them by Weavers, none could identify anything other than the Weaver just talking to them and perhaps providing them with a few relevant brochures or contact points. They all considered just talking to the Weaver the most important type of support.

# 5.3 **Summary and conclusions**

All of the support is considered to be useful in some way as part of a package of support. The most overwhelming support by Weavers was for the responsive and flexible approach to the Weavers program adopted by TACSI and the Local Connector. The Weavers also highlight the Orientation and Learning Lunches as important tools for positioning them to successfully undertake the role of a Weaver and gain peer and other support. While Weavers may not use all the support tools directly in their matches with Carers, they noted that it informed their practice and was good to fall back on in times of need. The main criticism was the Loom, but if functioning adequately and with appropriate training, Weavers suggested that could also prove to be a useful ongoing tool. Carers identified just talking to the Weaver as the most important support they could offer.

# 6 Outcomes for Carers and Weavers

## 6.1 Introduction

Carers and Weavers were interviewed to identify what, if any, outcomes were experienced for Carers and Weavers (and potentially the person being cared for and the aged care system in general). The interviews were analysed using a Realist Evaluation approach employing context, mechanism and outcome configurations. The following aspects have been particularly explored:

- What are the characteristics of successful matches between Weavers and Carers?
- How might the support Weavers provide contribute to outcomes (if any) for Carers?
- What outcomes are generated, for whom (Carers, Weavers, the health and aged care systems) to what extent, in what respects, how and why?

# 6.2 **Data and findings**

Ten Weavers were interviewed about their outcomes: 3 male and 7 female. These were expected to be in active matches with Carers, ideally with at least one completed match. Six of these Weavers had completed one match, two had completed 2 matches and two were in matches that they described as 'almost complete' or 'fairly progressed'. All but one of the Weavers also had an additional one to three matches active at the time they were interviewed. Data on outcomes and mechanisms focus on the completed matches, although insight into possible contextual factors influencing the success of a match has been posited from the experience of all matches, as suggested areas to be further explored.

## 6.2.1 The characteristics of successful matches between Carers and Weavers

The particular characteristics of a match between a Carer and a Weaver provide an important context to how the program might work. Possible contextual factors that might influence the success of a match, (based on hypotheses developed from experiences during the development phase of the program, prior to the evaluation, as well as factors highlighted through interviews as part of the evaluation) include:

1. Simply having a lived experience of caring, which may assist the Weaver to understand the Carers' experiences and/or encourage Carers to believe that the Weaver is likely to understand;
2. Similar disability issue of person being cared for, which may increase Weavers' knowledge of specific issues in caring for a person with that disability, specific techniques that may assist with those issues and/or specific services that are available for them;
3. Similar relationship to person being cared for (e.g. spouse-spouse, parent-child), which may assist the Weaver to understand how relationship dynamics between the Carer and the cared-for person are likely to impact the caring relationship;
4. Similar interests outside of caring, which may assist the Weaver and Carer to establish a sense of 'kinship' rather than simply being 'peers' in relation to caring;
5. Certain minimum time period, long enough for a relationship of trust to be established and for issues to be worked through and addressed;
6. Demographic factors: such as gender, age, level of education or job type, which may again assist a sense of being a peer, or which may undermine it.

All Weavers are selected based on the assumption that they have a lived experience of caring, and of course all Carers have this experience as well. But the question is: is this enough for a match to lead to positive outcomes? The Local Connector noted in her interview that she aims particularly to also create Weaver-Carer matches that adhere as close as possible to the second factor noted above (for instance, if the person the Carer was caring for had Alzheimer's disease, she would aim to suggest someone with the same or similar issues). She is also particularly mindful of gender and personality factors and notes that the key element or elements in a successful match are trust and communication, the capacity to remain focused and to be flexible with each other's needs.

The current data suggests the more similar the experience of the Weaver to the Carer, the more successful the match seemed to be, including the achievement of outcomes. This would have to be further explored with a larger sample of Carers and Weavers where the outcomes for subgroups could be more effectively assessed.

In considering the factor of time, all those assessed were supposed to have completed the minimum of at least 12 weeks, but as noted previously, two were not necessarily 'complete'. Since all except one 'complete' match showed outcomes, there is too little information to suggest how much influence time as a factor has on outcomes, however, the minimum engagement time of at least 12 weeks does seem to elicit outcomes regardless. How or when a match ends may be a factor and there is currently some uncertainty already about how this all works. There is usually an organised meeting but despite this, some Carers don't seem to realise it has ended, and one Weaver suggested it perhaps just reached a natural end when Carers don't seem to need the Weavers' help anymore. One thing worth noting, is that a few Weavers established relationships that led into longer term relationships beyond that of the formal period. One Weaver, whose Carer showed two positive outcomes, developed a strong relationship with her Carer which extended into an ongoing relationship, as noted below:

> *"...actually when we completed the match we were quite sad that it was finishing and [the Carer] made a comment, 'Can I see you if I want to?' and I said, 'Yes, you can'. Which she has done. It's been fantastic." (Weaver 10)*

The idea that the more similar the situation (or the more of the 6 factors you have in the list above) could also be explored in future research with a larger sample of Carers and Weavers. Particularly whether the more quickly and easily a relationship is established, the more likely it lasts beyond the formal relationship to allow the potential for further ongoing outcomes. Certainly, there is a suggestion that where there is a mismatch of one of the above factors, there is the potential for the relationship to falter and no outcomes to result. This derives from the experience of one Weaver-Carer match for who the program did not seem to work. In this match, there were also some significant points of difference or misunderstandings that the Carer indicates may have contributed to its lack of success.

The Weaver reported that the reason for this was because the Carer's expectations did not match what the service offered: that the Carer expected the Weaver to provide a form of respite, spending time with the person being cared for rather than the Carer. The interview with the Carer suggests this was a factor, but that other contextual factors such as gender were a factor, as well as a misunderstanding that meant the Carer also didn't feel a sense of empathy form the Weaver with her situation. In the Carer's own words:

> *"We just spoke to a chap there and the lady in charge immediately thought oh well, we'll team you up with him, which I'd have thought would have been a good idea, but in retrospect my partner wasn't very responsive because it was a man. I'm sure he would have much preferred a woman...it was just someone else he perceived I was carrying on with – because of the Alzheimers you see. Paranoia....We did have a cup of tea and chat and that was okay but he said oh he thought we were very lucky to have each other or something but I didn't feel I could relate at all so...I didn't feel lucky at all, quite frankly, to find my partner has Alzheimers. Quite difficult...He rang a couple of times, but I need somebody to help me with my partner, but obviously it's not going to work with a man...Yes I really need somebody to come and sit with him to enable me to go out more. Yes, I didn't quite know what was on offer, I think it was just someone to talk to but...I didn't sort of feel the empathy I was looking for...That's no reflection on the gentleman I'm sure he's a very nice gentleman – just not what I wanted." (Carer 12)*

The Local Connector is aware of the circumstances surrounding this Carer and clarified that the connection with this particular male Weaver was made at a public recruitment event where the Weaver chatted to the Carer for some time. The Local Connector did discuss with the Carer if she wished to be matched with the Weaver as it appeared that they had already struck up a connection. The Carer indicated at the time that she was happy with this. It is part of program practice that both male and female Weavers are offered as possible matches to a Carer. However, where there is a limited choice available and when there is a gender difference, the Local Connector will confirm with both Carer and Weaver if this is appropriate. On occasion, the Local Connector has supported the Carer whilst waiting until a gender matched Weaver is available. The Carer in the above circumstance did note in the interview that originally she agreed to a match with a man thinking it would work. She knew she could have followed up and sought a match with a woman but decided not to.

The role of gender in matches between Weaver and Carer should be further explored as a contextual factor relevant to the program theory. One of the male Weavers (for whom the majority but not all of his complete and active matchups, have been men) noted there may be different constraints or different types of emotional support required appropriate to gender or gender roles. He notes in relation to the men that he has worked with:

> *"…we face different situations in a caring role than what women do, because we think we know everything [and] they find it difficult to recognise they need support. [Often men need the reassurance that] "maybe you're doing better than you think you are". (Weaver 9)*

Something that also should be further explored is whether those with relevant professional backgrounds (such as in aged care or other caring professions) find it easier to compensate for any lack of common ground with their knowledge and skillset, as some noted that they had had to apply their professional skillset to develop relationships with Carers that might have proved more difficult for other Weavers without other forms of experience with these issues (for instance, specific mental health issues).

The way Weavers speak about their relationships certainly suggests that maximising the number of characteristics above seems to enhance the connection and enable strategies to be imparted via lived experience stories. One Weaver, matched by gender with two Carers who have completed the program, and by a similar work background for one of these, noted:

> *"And common ground with both of these people is that their mothers have dementia [and, like me] they've both got very close relationships to their mother and so it really gives you a common ground to work with. Therefore there's often common things to talk about in the strategies to support the father whose wife is changing dramatically due to the onset of the disease". (Weaver 4)*

Reflecting on what all Weavers highlight, one Weaver notes the most fundamental aspect of a successful match as: "…having a similar experience is certainly the key to the match, [it's] the lived experience." But is it enough? A couple of Weavers suggested that simply having a lived experience of caring was sufficient to establish a Weaver-Carer relationship that led to some outcomes. However, one of them also noted that the Carers are fully engaged in choosing who they want ("The people choose who they want"). This can potentially overcome any lack of common ground apart from the fundamental requisite of having a lived experience of caring. Indications are that the Weaver and Carer who were unable to establish a connection were placed together because, according to the Carer, there was a level of obligation on the part of the Carer as they had met the Weaver at an event and developed a rapport there in front of the Local Connector and so did not go through the usual process. Notably, this had also happened in at least one other circumstance and that time the match still led to positive outcomes.

Not having other things in common did not necessarily preclude the chance of success. This example is provided, by a Weaver:

> *"The first person I was matched up with was like a bam, you know, my situation and her situation were so similar. And she was like 'you're the first person I've ever met who's in a similar situation.' So that was a really, really, just a really close match on the surface…And that [made] a close…match. But the last match I was in…I don't know why they chose me. I mean we got on like a house on fire and we made some pretty dramatic changes very quickly but I was sort of thinking well it was a couple and I've never cared for a partner. He had Parkinson's. I've never cared for someone with Parkinson's…And yet it worked like a charm…I just feel that the three matches I've had have been very, very different, all three of them. And that every single time the number one thing is just that experience of being a Carer [but] it might matter to the person who's choosing a Weaver. They might think "oh, only someone who's done this or that would understand." And then if they get someone who has had whatever they think is so important then they'll feel more confident about the match. But I feel a little bit as though almost – not quite perhaps – but almost any Weaver could match with any Carer. With the exception of things like if someone says "I'm not having a man in my house" or…religion or something." (Weaver 6)*

One Carer, despite her initial reservations about a possible difference in, or conflict of, personality (she was introverted and the Weaver was rather extraverted), found that this did not prevent a positive relationship from being established and leading to outcomes:

> *"At first I was daunted because she was bubbly, but then I realised she's gone through a lot and she was always there...even if I wanted to ring her, which I tried not to, because I was still nervous about it all, she was always there and she made a point of ringing, I think initially it was twice a week...and then just once a week. She was good because at one point when things were really going bad for me, I just said look I can't talk, and she let me do that, she allowed me to hang up and I said I was sorry but she didn't tell me off or anything...She seemed to know everything that I was going through, because she's been through things too. No, she was perfect...Yeah I was surprised because of her personality, she's so bubbly and very outgoing, it seems, and I'm different, and I thought, oh I don't know about this, but it was the perfect match for me anyway...I think it's because she's gone through it...I guess it was because of that and she was very caring person". (Carer 9)*

## 6.2.2 Other contextual factors of relevance to the Weavers program

A few of the Weavers highlighted the importance of the flexibility of the program. If this was to change, this may influence how well the relationship works, how engaged they are in the program and whether outcomes are achieved. One Weaver said:

> *"I liked the flexibility. I think that...this is the best thing that I've ever been involved in as far as there are no...constraints...just the fact that it's not a regular Tuesday [and] I could quite often, after what I pack into my week, 10 o'clock at night I could be sitting there reading an email from my match and just sitting back and then typing out something to send to her which I know she was going to fit into her day the following day...and I think it was just she was so overwhelmed that once she would get on a roll...we could go all over the place, so at one of our coffee mornings...she said to me, 'Oh, look, can you email me what we've talked about because I leave here and there's so much going on in my head?' So that was something that did work for us because I'd pick out points that I felt were relevant to the match and what she was looking for and then I'd email her that and then she'd come back and that went on with our entire match...I could get two pages of information ... and probably a half a page would be the real relevant stuff that she needed to do and I don't know where it came from, but I seem to have the ability to pick out what she needed...and answer that and send back. So that worked well for us". (Weaver 5)*

Another contextual factor noted as a potential key to the program's success by one Weaver was the extensive experience and professional backgrounds and knowledge of the Weavers:

> *"I think it's quite interesting that most of the people from that room have some sort of either professional or very extensive voluntary experience that is relevant to the – what would you call it – into the caring context. A lot of them that worked as Carer coordinators, they trained Carers, they've worked as a Carer in a nursing home for years and years. The people just...come from very, very different backgrounds but there's nobody whose just sort of like oh well, I'm just a person who happened to have done some caring. They've all got something and it's not always obvious straight away. Sometimes you might meet someone four or five times and you go oh, that's where your depth of knowledge comes from or that's where your depth of experience comes from or that's where your skills in this or that area come from. They are bringing something to the table beyond just being a Carer...Which means we will all learn from each other all the time". (Weaver 6)*

A second Weaver highlighted both of these factors in action in her matches:

> *"All of them have worked really well. Some of the match ups, all I've done is phone calls and a couple of meetings, not much, but they've all said they got something out of it. And you're a bit puzzled because all I've done is talk to them, but I realise that the feedback is that that's really all I've needed to do...In some cases I have used a lot of my nursing skills and aged care knowledge as well, particularly about what's available. Well, just talking about what's out there for them and often they're resistant to use things, some of the Carers think they have to do it all for themselves...one of them had all the services known to man but I still had a role as well." (Weaver 3)*

Another factor noted by one Weaver was that an essential component of the program was a focus on Carer wellbeing rather than outcomes relating to use of services:

> *"...something I would not like us to lose, is the focus on Carer wellbeing. That's where it started. Because at one point somebody mentioned evaluation at a Weaver lunch - not one of the Weavers. Like how successful have you been in keeping people out of nursing homes? Well that's not our goal. If the best thing for a Carer and the person being cared for is for that person to be in a nursing home then that's a positive outcome, that's not a failure. You know it's really important to remember the intent of the program and not to be distracted by what the government of the day thinks is important or whatever. That the end purpose is to improve the wellbeing of Carers and to stay true to that." (Weaver 6)*

The new program theory notes that the context of feeling understood, that someone 'gets it' and provides non-judgemental support is the essential basis upon which the mechanisms work. 'Feeling understood' could mean that the Carer felt they were listened to, were not being judged, were not alone, and/or not the only one going through a difficult caring experience. Having this experience helped the Carer to be open to the Weavers' knowledge and experience. Therefore, these factors are discussed in the mechanisms section 6.2.4.

### 6.2.3 Carer outcomes from survey

Despite there being insufficient data to analyse the two versions of the post program surveys individually, there were a number of questions which were asked in both versions of the post-program survey. All the questions in this section used a five point scale ranging from ‘not true for me’ to ‘true for me’. The middle point was ‘unsure’.

Even with data from both surveys there were only ten respondents so the analysis presented here is necessarily limited. Not all respondents answered all questions.

The table below shows the frequencies of responses for each of the questions.

Within the very small number of respondents, Carers were more positive about having learned new skills or knowledge than having learned about or used new services. The exception to this was having learned about new services for themselves. However, only two respondents (25%) indicated that they had requested a new service for themselves.

**Table 11. Services and Knowledge**

| | Not true for me | A little | Unsure | Quite a lot | True for me |
|---|---|---|---|---|---|
| I learnt new ways from my Weaver to help manage own stress | 1 | 1 | 1 | 6 | 1 |
| I learnt new ways from my Weaver to help the person I care for feel less stressed manage the stress of the person | 2 | 4 | | 4 | |
| I learnt new ways from my Weaver to help the person I am caring for | 2 | 2 | | 4 | 1 |
| I learnt new tips about how to manage symptoms or behaviours of the person I am caring for | 1 | 3 | | 3 | 1 |
| I learnt new information from my Weaver about the obligations of organisations that provide supports to me as a Carer | | 4 | 1 | 3 | |
| I learnt about new services for myself | 1 | 2 | | 1 | 4 |
| I have a better understanding of how to access services for myself | | 3 | 1 | 3 | 2 |
| I requested a new service or services for myself that I had not requested before | 4 | 2 | | | 2 |
| I learnt about new services for the person I care for | 3 | | | 3 | 2 |
| I have a better understanding of how to access services for the person I care for | 2 | 1 | 1 | 2 | 1 |
| I requested a service or services for the cared for person that I had not requested before | 4 | 1 | | | 2 |

## 6.2.4 Mechanisms and outcomes from interviews for Carers

Both Carers and Weavers identified a range of outcomes from the Weavers program that were somewhat in sync with the proposed outcomes from both the original and the revised program theory. Table12 summarises the reported outcomes for Carers. As can be seen in the table, no Carers reported negative outcomes, however, one Carer that 'completed' the program was reported as having no outcomes. This was the result of an unsuccessful match which was discussed in section 6.2.1.

One outcome for Carers proposed in the original program theory was that they would take increased time for themselves. It is proposed, based on the findings, that Carers taking increased time for themselves was not the only way in which Carers in the Weavers program were better able to assert their own needs. This outcome of increased assertiveness about their own needs is highlighted above and was the most common outcome noted by both Carers and Weavers (eight out of 13). It could include that the Carer: took more time out or were doing more things for themselves; came to realise their own limits; or took steps that prioritised their needs (or better addressed the needs of the person being cared for, which addressed issues for the Carer).

**Table 12. Outcomes for Carers identified in the interviews**

| Outcome | No. Carers | Example from Carer or Weaver interview |
|---|---|---|
| 1. Increased assertiveness about own needs | 8 | *...because she was an elderly lady, and had blood pressure and was travelling on a busy road, she really wanted to get [her partner/the person being cared for] into a home closer to her. So I encouraged her to ring and she said to them 'I'm not wanting to change because I'm unhappy, I'm not a person that complains...it's just for my health'. And I also suggested to her that she get a letter from her doctor stating that her blood pressure was not good and that it's a struggle for her, and anyway she did...and just kept persisting until she got him in a place that was only 5-6 minutes by car and that she could walk there... [Weaver]* |
| 2. Less stressed | 2 | *[Before Weavers she] seemed to be absolutely ridden with guilt that she couldn't do more for her mother...she had quite a few medical issues that she was dealing with...and there were days that she would have to go to bed and not be able to get up and...she said, "I should be showering my mother and I should be giving the medication...[and then after] just pointing out sometimes very minor things that seemed to help... she seemed to be more settled. [Weaver]* |
| 3. Increased optimism | 2 | *It's possibly made me a bit stronger, in my views...I was always thinking that... possibly more negatives than positives. So I think I'm better in the positives area... about [the cared-for person's] welfare and my own welfare as well. [Carer]* |
| 4. Decreased sense of isolation | 2 | *...yes, I felt isolated...and now I run my own...seniors group...It takes you out of the house, rather than go nursing home every day...and Weavers was one of those things that got me to that stage... [Carer]* |
| 5. Decreased depression | 7 | *It's made me sit up and not mope around doing nothing...and get on with your life. I got that from [the Weaver] and that's what I'm very grateful about. [Carer]* |
| 6. None | 1 | Refer section 6.2.1 |

*Only four Carers identified one outcome, seven identified two outcomes and one identified three outcomes.*

Seven Carers reported decreased depression as an outcome. For each of the remaining types of outcomes – decreased stress, increased optimism and decreased isolation – two Carers reported these as outcomes.

The revised program theory proposed that there are four possible pathways that help create outcomes for Carers through the Weavers program. That Weavers help the Carers to:

1. Navigate and negotiate the service maze
2. Stay connected and involve others
3. Work through the emotional challenges
4. Sustain things for themselves

The major strategies that Weavers applied in order to achieve outcomes were:

1. Adaptive caring: supporting the Carer to undertake problem solving – to address their problems by trying out new methods to help them gain a sense of control
2. Narrative approach: journey mapping in which Weavers and Carers identify what they have drawn upon in the past or can draw upon in the future to overcome challenges in their caring journey, including identifying strengths and types of support (Carers can learn from Weavers as an example of someone who has been an expert in their own life, experiencing similar challenges).
3. Ambiguous loss: helping the Carer to cope with the emotional side of the caring experience and to regain their identity, hopes and dreams.

### 6.2.4.1 Navigating and negotiating the service maze

Below are three examples of how navigating and negotiating the service maze worked in the program.

In the first example, the Adaptive Caring approach was particularly important in highlighting the Carer's rights and encouraging the Carer to set limits and say no to doing things that services can or should be doing, thereby asserting her needs:

> *"It's had great impact for me I've been struggling in and out. She came along at the right time. I was a mess when I first saw her. Learning to say no and looking after myself more. Mainly the no was a big thing because I've never been able to that all my life. I've learnt to do that, in a nice way. I have learnt a lot from the Weaver. She has guided me to telling [the staff in the nursing home] that I don't feel that good, from time to time...[I was having to dress him because they were showering him late]. That has come a lot better too...they're thinking of me as well, because they know I struggle [now]. They're nice girls, we've got some kind of connection with some of them and they understand but I don't think they'd realised how bad I was...kneeling down to put on his shoes and clothes, I was puffing and panting...I'm not the sort of person to tell them I've got an illness...but I don't think they realise...though they do now. The other thing is, down at the nursing home, because he's mentally very well, he'll tell me a lot of things, complain to me and I finished up having to speak to them as well [about those things too]. She was very gentle about things...I guess I knew it in my own mind what I had to do, but I've never been able to do it. Her encouragement helped me...She has encouraged me to try and do a bit more, other than go down to the nursing home and be in the house. After Christmas, I'm looking into a couple of things...card-making...exercise classes...joining a gardening team...Often I'm too tired to be bothered [but now] I know where my limits are and why I've had to learn to say no...it [made] me feel more positive about myself". (Carer 11)*

The following example shows particularly how the Weaver's example has enabled the Carer to navigate and negotiate with services. The Carer has started to emulate the Weaver's attitude and behaviour, recognising that these are skills and strengths they can draw upon in their own journey, to address any issues and ensure that both her needs and those of the person she is caring for are met. This Carer also feels a sense of isolation in their role as a Carer – a context which occurred often in the interviews (from a realist perspective, this identifies 'for whom' this program seems to be working). Also highlighted in this example is the benefit of talking things through with someone who 'gets it'.

> *"I knew because of her personality...my mother would always be tough...I discussed this with [the Weaver] and...so I guess I just have to keep talking about it, and in talking about it, I find different ways of approaching my mother...the only way I work in understanding what is going on is just if someone talks to me, I may not all completely understand it...at the time but I digest it all afterwards and something from there comes out and I do start to do things with my mother, say that [the Weaver or the Local Connector said]...I'm making all these appointments with all these people, because I want a definite plan for my mother and before I was relying on them to say 'oh,*

> *she's doing well' and 'she came out to lunch today'… she's not doing well, and I want to know what they are going to do for her and…I will do all I can… [the Weaver] has helped in that way because she's a strong lady and she knows how to stand up for herself and ask questions…I'm learning a bit like that from her. A few times, she's given me a little saying and every now and then I think of it so that I can feel a bit more confident. When I do get down, I think of the little sayings that she's given me and that makes me feel like to hell with everyone, I'm standing up for my mother…I don't think I could have got through any of this [without the Weaver] because I have no-one, no-one, to talk to here in Adelaide." (Carer 9)*

A further point this same Carer makes is how different the Weavers program is from other organisations:

> *"If they were to give me a pamphlet and I had to go to an organisation and just like you said at the start, it's too much information to take down. I've noticed with a lot of people they're always typing in their computer what you're saying and it just takes away from the talk that you're having with someone and you're trying to express yourself and then you see them typing away and it doesn't feel good and with [the Weaver], you just talk and it's good. It makes the situation when we talk like you're talking to a real human being". (Carer 9)*

This Carer also notes how the Weaver helped her through the Adaptive Caring Loop (as per the revised program theory) to come up with new ideas, to understand her entitlements and shift the power balance away from the service having all the 'power', to the Carer being able to feel entitled to assert their needs and advocate for the needs of the person being cared for. Helping Carers understand what they're entitled to, which enables them to feel entitled to and validated in their request for support, was a part of the original program theory which has been borne out here.

> *"And even when my mother was put into a home, [the Weaver] knew about the company and things I brought up about situations in the home she was able to guide me through it or tell me, 'no, you're entitled to this and that'. I was so glad I had her…I think it's more her experience, and then just talking to her, and understanding that I have a right to know this about my mother and that the home is not always correct…and I can speak to…the people in the home that I can talk to them about my mother, about what I feel is going on. And even though they say one thing, and I know something else is happening, she's made me feel like I can voice my opinion because I'm really basically a shy person, and I have to get over the fact that just because they're in authority doesn't mean they're always right because I have to stand up for my mother, because she won't and can't.*
>
> *She's (the Weaver) made me more confident in dealing with these people although it's damn frustrating at times…It's just her talking of her experiences, and me getting a feel of having someone else giving a different opinion and not relying on my own thoughts all the time…I think I work better in that situation where I'm talking to someone [then] I go back, and I just think about was said and then I can work out what suits me and what doesn't. Sometimes if someone gives you information of how it's worked for them, it doesn't always mean that it's going to work for you and you have to find a way to, with the knowledge she's given me, to make it to suit me and my personality…because a lot of the times I would never have thought of what she's said…You don't see everything and she helped see different…to open up a bit and see what can be done. [The] one thing that everybody says: you have to look after yourself, but that's the one thing I can't do yet". (Carer 9)*

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*8 This theory as a concept is relatively new and may need further empirical research to validate it.*

A few Carers noted the feeling of being overwhelmed by services and options as a problem for them when they first became a Carer, and for one of these, a male Carer, use of the Adaptive Caring Loop to assist Carers to navigate and negotiate the service maze has some similarities to the 'Paradox of Choice' theory. The Paradox of Choice (Barry Schwartz, 2004) is a psychological theory which posits that happiness may lie in limiting our choices, which are otherwise ever burgeoning in the modern world[8]. In the example below, the Carer was feeling overwhelmed by all the services, information and advice on offer. The Weaver helped to sift through what the Carer had already done and identify that the steps he had taken were appropriate and the best he could do in the circumstances, then provided some minor suggestions about other steps. This example from the Carer's perspective demonstrates adaptive caring in action and provides some hints as to how the Adaptive Caring Loop and the 'paradox of choice' concept might be at work in the Weavers program:

> *"...because when you first come into this situation and everything's coming at you, at a hundred miles an hour, and you get hit with brochures. And I started a filing cabinet...these ledgers...and I think I got six or seven of these things, that's how much gear I had. And the minefield, to go through all this, you get so confused and everybody's in the same boat...It's just everything at once, including Weavers...it was just full on, it's just too much. Now [I'm just] turfing it out, a lot of it's not relevant, services you don't need...Having [the Weavers program] was a big plus, just to talk in general to them, nothing in particular, just across the board. And that was a good plus because [the Weaver] had been there and done it, whereas the staff [of a caring organisation] admittedly hadn't been there and done it...they probably knew all about it, but they probably hadn't experienced it...I know my head was in a blooming whirl at the time and it just takes time to get over that. I think they were a help in the beginning, to get me on the road, to get me going..." (Carer 13)*

Their Weaver highlights this as well, and notes how it works in the context of feeling understood:

> *"I think the mechanism was that [we] could see what they couldn't see and that was that they'd stalled. They were competent people, they were problem solvers, but there were too many problems happening all at once and they'd lost the ability to cope and so [they'd been referred] to Weavers because they were failing to cope on things that they should have coped with like getting respite and getting someone to clean the floor. They'd got locked in on obsolete thought processes like I promised that I'd always scrub the floor. But that was when you were 40. Now that you're 75, you've been let off. So we were able to, I guess, firstly demonstrate a lot of comfort in our lives and they could see how we managed [and] we were very quickly able to recommend five easily achievable steps...we didn't nag. On each occasion we just chatted and on each occasion they'd brought up the issues that we'd originally discussed and one by one the issues were addressed...And a lot of it was just generally debriefing, hearing their complaints about the system and the lack of understanding on the part of the family. So it was building confidence in us and us building confidence in them, yep, leaving it, easy achieved steps and then congratulating them as they achieved the steps... "And they asked questions, how the hell did you manage? well ... this was difficult but you know there's always a way you know if you try hard enough. We weren't setting out to change their lives, we just answered the questions honestly and they said that they thought their living conditions were easier than ours...and I saw that as being the big success..." (Weaver 7)*

### 6.2.4.2 Staying connected and involved with others

The example below shows how staying connected and involved with others (or repairing and working on these connections) can achieve outcomes. This Carer demonstrates how important the similarities of the relationship with the cared-for person, and other Carers involved in that person's life, to the Weaver's experience can be an important context for Carers:

> *"I think the thing that we had in common more than anything was the relationship with the father – who is the main Carer for the person with dementia. The two fathers seemed to have similar personalities, in some ways not terribly easy to encourage to get supports for them and the person that they're caring for which could be a male thing as well..." (Carer 8)*

Here the Carer describes how drawing upon what the Weavers' approach had been to overcoming challenges with her father through her caring journey, had enabled her to shift the focus of her journey. She now aimed to work towards better connecting with her father who was the other Carer:

> *"[The Weaver] gave me quite a few tips on how she handled talking to her father and broaching the subject of getting some support...when maybe they were reluctant or resistant to it. And handling stressful situations like when you were working together, even getting the evening meal and things like that where it can sometimes get a bit stressful...they do it one way and they do it a different way and things can just blow up. [The Weaver] had very similar situations with her father so it think it made me step back and say no, you're handling things wrong way and...look at the situation and re-evaluate how you handle the situation when those sorts of things happen. It was more sharing of those experiences she'd gone through and being in a very similar situation... Definitely made a difference...A more positive outlook about everything. Where even I guess with the work life it...extends into work because if less stressed...with what's happening at home, then going to work and handling what you've got to handle becomes less of a burden because you're less stressed in your personal life too." (Carer 8)*

### 6.2.4.3 Working through emotional challenges

The quote below demonstrates how working through emotional challenges a Carer who had experienced reduced isolation (referred to above). This Carer also demonstrated increased assertiveness. This example highlights that the basis for achievement of any outcomes is that, first, the Weaver 'gets it' because she's been through it. An important context for this Carer is that the support is not coming from a paid service representing the cared for person, or a family member/someone in their social circle who might judge them, but from someone external who provided them with a supportive environment. In this example, the Weaver role modelled how they 'got through it' and also imparted their understanding and knowledge of the services and support for the person being cared for, which built up the Carer's confidence to talk about it and helped the Carer feel entitled to seek and accept help and assert their own needs – that they have a life to get on with and not feel guilty about that (dealing with the ambiguous loss):

> *"[The Weaver] was probably the first person I met that had been through it...That was hard, what we were going through, [and] yes, I felt isolated. [I knew] if I really need [the Weaver] I could call... And I knew she meant it. I knew it was genuine, I knew she genuinely cared what was happening... you knew that well, she's got through it, I can get through it too...until it happened to me I would never have thought of going to ask somebody for help, you always keep everything 'in house'.*
>
> *But this is a totally different situation, you need to have somebody that's not attached to you... Somebody not close to you that I felt I could really open up to. [I know others who went to a Carers group] but I never went to that, Weavers is the only thing. Because it was personal, they visit your home, I never wanted to go in a group and sit and talk...Anything she shared with me was very helpful...she opened up a bit about her own life and her husband. She didn't hold anything back. She shared, about what went on when he went to the nursing home. She had a very good understanding [and] she built up my confidence, she's given me a bit more confidence to open up and talk about it - about what was going on in me. And I wouldn't have done that in a group before, I would have just sat there and listened to everybody else...At the nursing home they have this group thing but that's alright, I can handle that now because that's related to the nursing home and what's happening there. Whereas before I couldn't have done anything like that.*
>
> *I have a life to get on with – which you don't think about. Your husband is your life, but I have to make a life for myself. To try my best not to feel guilty, there's lots of different things like that you're going through and it's things like that you don't talk to family about because you feel guilty... They don't want to hear that you want him to go in a nursing home – but you know he's getting the best care...and now I run my own...seniors group...It takes you out of the house, rather than go nursing home every day...and Weavers was one of those things that got me to that stage..." (Carer 7)*

The below example in which working through emotional challenges is particularly profound, highlights the benefit, as noted once before, of the program not being attached to a mainstream organisation, and also the benefit of the program not offering 'advice' but ideas, support and feeling understood, which led in this case to validation, affirmation of what they were doing, and an outcome of decreased depression.

> *"When you're caring for someone 24/7 it becomes difficult to see the wood for the trees... it's easy to get very flat or depressed...and the fact that somebody can come and can validate what you're doing and the other thing I'd say is the person that's validating it has no axe to grind because other organisations, quite frankly, that you go to, they might be offering a service...and theirs is the best. Whereas if you go to somebody, like the [Weaver who] didn't have anything to gain from me doing anything was able to sit there and validate what I was doing because you're on your own... [The] key way [Weavers helped was] emotional support...[the Weaver] reinforced the fact that when time came to put [the person being cared for] into care that I'd actually know it was time and he went into the bit about all the guilt I'd feel and how upsetting it would be and...he was right...What my problem was...I don't think I was feeling depressed, or yeah I suppose I was, feeling out of my depths definitely.*
>
> *The problem that I faced...was I was getting oodles of advice, gratuitous most of it, from people who hadn't been in the position I've been in. I got sick to death of people telling me, 'you've got to look after yourself', 'you've got to do this, you've got to do that'...in actual fact, in some cases that produces more strain and stress on an individual like myself than the actual process of doing the caring. And so you begin to think you're not doing a good job, you don't know what you're doing...then after telling the Weaver about my situation they were able to sit down there and say 'from where I'm sitting, I think you're doing a really good job. You're doing the things, you've accessed the things that are available, and possibly there's not much else, really, that you can do.' So that was what helped me.*
>
> *There's all this sort of assistance out there that you don't know anything about, that you don't know whether you ought to try and access it or not and you begin to think that you're a failure at caring... The fact that someone was saying you're doing the right thing...you're not making a hash of it...to have somebody who's been through all that to say 'oh yeah, that's good, you're doing it the right way', and make a few suggestions but the suggestions, I don't remember what they were but all I remember is they were fairly marginal to what I was doing... The Weaver has been there, they understand what you're going through and they can see and understand what you're looking for and that to my mind is what the benefit they've got to offer is. And a lot of the professionals you deal with have not been there...I don't want it to come across that other services don't provide help – I had lots of excellent support from professionals. But the stuff that I got that helped me, I got from the Weavers." (Carer 4)*

Working through the emotional challenges also seemed to work for the Carer who was a self-Carer:

> *"[The Weaver] she just listened, she understood... we did have different ideas...but it didn't make a difference. 'If it is what you want' she used to say to me 'it's what...you need' [and] I shall do my best to go find that...there were quite a few issues, some didn't get resolved, but at least she got it to the end point where I could think about that particular issue and think okay, that's as far as I can go with that until I could come up with another solution... it was nice to have somebody to tell my problems*

> *and say...gee you're a really positive person, which I am, because I haven't had the chance to share that with somebody what my life's been like, all my concerns...and where to from here...my family's not supportive at all. There's not anybody I can talk to and trust...So the Weavers even just talking about what the issues are, that was fantastic...to be able to talk to people and they just listened and they understood where I was coming from, and they didn't have 'oh well this is how I'd do it', which is what I've experienced throughout my life...They weren't, gosh well, you should be doing this or you should be doing that, or not saying anything...I never felt like that...people are judging me all the time but there was no judgement, nothing negative about the whole experience..." (Carer 10)*

### 6.2.4.4 Sustaining things for themselves

The example below shows how common experiences between Weaver and Carer led to a shift in the Carer's understanding of the consequences of the disease of the person they were caring for. This then changed their perception of the person they were caring for, thereby creating a shift in perception that meant they could sustain things for themselves, resulting in reduced stress. This quote also highlights, however, a couple of difficulties inherent in the program:

- the need to build a relationship with a stranger in a short space of time where you feel comfortable enough to share very personal information; and
- the tension between the provision of information and ideas versus just letting the Carer talk and offload (suggesting this must match the Carers' needs to enable the program to work).

This Carer says:

> *"It's a fairly intense program, you meet a stranger for coffee and it's really hard to know where the other person is coming from...So it's a fairly hard relationship to develop quickly in that environment, but the pressure is on you because it's part of a program...to get something out of these sessions, whether it's for me as the Carer, or even for the Weaver who's got a role to play as well... You don't really know anything about them, they don't really know anything about you and from the point of view of providing information about services, clearly that's an important part of this – it's not necessarily something I needed. I needed somebody who was non-judgemental...that I could just offload on. I just needed somebody to talk it through with, rather than necessarily looking for solutions. That's in the beginning. Towards the end I found that just hearing – eventually [the Weaver] opened up about her experiences and I was then able to adapt some responses from that which were helpful to me. And hearing what she had done...I found some commonalities there that were symptoms of the disease and I found that very, very useful. It helped to me to be more tolerant of some of the things [the person I was caring for] was doing. So hearing of somebody else's experience is just as important as having someone listen to yours...It's really important that you get the chance to speak with someone who is uncritical and has a shared experience...I certainly think that somebody who can provide personal experiences to demonstrate behaviours and attitudes and so on is a great incentive to see things from a different viewpoint. So I guess that's what it would be. And as I said, the need to talk with somebody is overwhelming and people who are not going through it, just don't get it...you would be considered to be disloyal, or whatever." (Carer 1)*

These quotes are all consistent with the finding in the survey that Carers were more likely to identify having learned new skills or knowledge rather than having learned about or used new services.

## 6.2.5 Weaver outcomes from interviews

Weavers identified outcomes including:

- a sense of purpose/meaning (for nine out of ten Weavers);
- increased confidence (four);
- social benefit (three); and
- reciprocity (two).

A possible mechanism through which outcomes for Weavers may be generated is in coming to feel valued as Carers. It appears to provide them with an avenue of recognition and support as past or present Carers, which they were lacking or did not feel during their own personal experience as a Carer. Two Weavers provide examples of how feeling valued increased confidence:

> *"Probably to think that there is value – no, and I shouldn't say that, I do know there's value in people's stories, I didn't realise that there was value in my story, which I think there is now and I think*

> *that's the greatest thing, and just mixing with like-minded people, though I do a lot in the aged care sector and it's been – my whole experience with my parents in just the last 20 years have been a big learning curve, so I suppose this was just another facet of learning how to navigate the system and the experiences people go through…For me, I didn't ever really think I had that much to offer anyone, that was just my lived experience and there's so many people are living that experience, but just some very simple things that I would say to her, she seemed to find an overwhelming truth in it and that gave me more confidence to probably approach her with different things and to point different things out that I may not have done…" (Weaver 5)*

> *"I love it. I enjoy it, I enjoy the camaraderie too…the thing that I get satisfaction out of, more so than anything else, at the top of the list is helping those Carers…passing on my knowledge, my wisdom and my advice to them and I see that they've taken that on board and as a result something has changed, then I see that my job is done and I get some satisfaction out of that [and] I feel so good about myself and helping everybody. It gives me a tremendous boost. To interact with all the other Weavers as well is great stuff. For me personally, it has done me a lot of good; it's kept me in aged care. It's wonderful when you know that something you've said or done has had an effect – it just gives me a boost…It builds your own confidence up a bit. When you help somebody else out and you see the changes…it makes you more confident. That in itself is its own motivation to keep you doing what you're doing. For me personally it's just been very rewarding, and I think when it's rewarding for you…that reflects back on the people you're looking after." (Weaver 2)*

Weavers also see inherent value in the concept because they recognise that they too would have benefited from it in their own situation and so they feel good about being able to use what was, for them, a difficult life experience and huge learning curve, to help others like themselves. Two Weavers provide the following examples:

> *"…just that the simplest thing can help someone… you don't have to look to professionals for advice alone, that there are people out there that have got something that they can share with you and it's an enormous help sometimes [and sharing that makes] me feel good because I think sometimes the journey of a Carer can be a very, very lonely experience, even though they've got people surrounding them it can be a very lonely experience, so to be able to help someone just not feel so alone or helpless, it does give you a boost if you think to yourself, oh, I've done a good job there…what I've said really helped. And I think it also gives you the confidence to think…okay, I've done this once I can do this again". (Weaver 5)*

> *"I didn't recognise it at the time [the person I was caring for was dying, but] it was quite a lonely process because family weren't supportive and all of that stuff…I've worked in aged care and I understand a lot about the system. I was given no respect – no ability to contact professionals about what was going on and it was just a battle every week. [And because they knew my background as an aged care worker] there was an expectation that they wouldn't need to do anything for me because that's not their job - they didn't understand. There's a lack of compassion and understanding that it's a family thing not just the person they're looking after…[and the person I was looking after didn't] die well so being able to talk to people that have been through it has been quite a good practice for me as well. I wanted to do something because – if I knew how to be activist I would be…but just being able to use that energy in a positive way to influence, hopefully, eventually, services… I mean I don't think I'll ever change that but…it's nice to educate people because…they need to understand what's happening to the person and that certainly didn't happen [in my case when I was caring]." (Weaver 3)*

Reciprocity may also have a role as a mechanism:

> *"I think I've probably been given insight into my own caring situation…I've probably gained more confidence and…learnt a lot. And maintained my confidence in just how much I have learned because it's not the sort of thing you learn out of books; it's called practical experience [and from that I] get a lot of fulfilment and satisfaction. And you're sharing with like-minded people." (Weaver 9)*

This idea is supported by the Local Connector interview, when she spoke about Weavers:

> *"There's a real sense of giving something really valuable back to Carers...because they've been in a situation where there wasn't anyone there for them, and they struggled, they don't want to see that happening to others...using their own experience and story is part of that and I think it respects the love and care that they had for the person that was in their life [that they cared for] in some ways, it's like paying it forward. There's a real sense of community as well, like they're a family, they look out for each other. We really value their input as well, and it's on an academic level, and it's good for them too because a lot of our Weavers are very capable people, not just from their own experiences, but professionally...for a couple of Weavers it's a good connection for them because they've lost somebody in their own lives." (Local Connector)*

### 6.2.6 Outcomes for the people being cared for

Through the Weavers program it was hoped that there would be outcomes for the person being cared for, such as better or more ongoing support and access to appropriate services which leads to an improved quality of care. This aspect was not within the scope of the current evaluation and so the survey and interview instruments were not developed to extract information specifically about the person being cared for, however, some outcomes were referred to in the interviews with Weavers and Carers. The most common Carer outcome identified by Carers in the interviews was increased assertiveness about the Carers needs (8 out of 13) which often lead to Carers seeking increased supports or services for the person being cared for so they could address these needs. This outcome therefore has particular consequences for the person being cared for and for the aged care system more broadly. For many Carers this involved seeking increased help which often included support from aged care or other relevant services for the person being cared for, such as respite or moving them into an aged care home, to enable the Carer to have the capacity to participate in other things. Examples are provided by Weavers below:

> *"[Although the needs of the person he was caring for were becoming more substantial, the Carer] was determined [the person he was caring for] wasn't going to respite or in a nursing home. But the result is, she is in a nursing home...[the person being cared for has] settled really well. I count that as a big success." (Weaver 9)*

> *"[The Carer] has been taking time for herself and also – her mum's still at home – recognising that she does need to ask for help. Whereas before [the Weavers program] she was sort of saying 'we'll be right'...between dad and me we'll be right. Now she's thinking we really do need help and we do need to move forward with it". (Weaver 4)*

As can be seen from the examples provided above and in the previous section, Carers who are able to assert their needs are more likely to recognise when they need assistance for addressing the needs of the person being cared for, and this can lead to improved communication with existing services or result in them making decisions about accessing services. They are also more ready to seek emotional or other support for themselves (such as support groups) or to gain a different perspective that makes them better able to cope rather than flounder or struggle to cope by themselves which can lead to Carers being unable to support the person being cared for in the longer-term.

Another significant outcome for Carers was decreased depression (increased emotional wellbeing). When Carers have improved emotional wellbeing it is likely that they will be able to better care for the person they are caring for and enable them to sustain it for longer. The other noted outcomes such as reduced stress would also have a similar impact.

Another Carer describes how they have a changed approach to the person being cared for which helps them to cope better with caring and also how this has led to an outcome for the person being cared for:

> *"...she's as stubborn as always, and especially with me as always, [but] she is coming out, for the first time she was participating in that other thing and she enjoyed it and was complimenting other people instead of thinking of herself and for that moment she was enjoying herself [but as a result of the Weavers program] I will keep trying to do that. Even getting her to the hairdressers is a real hard thing every fortnight, but I always try different things and each time it's something different. I have to keep trying...I have been like this before when I was looking after her at home but even though you're [just] visiting...[now I] keep [my] eyes and ears open, for different clues that she gives: oh, maybe next time I could do that...Even though I'm visiting my mother, I'm always on the look out to help her...and bringing her different things we can do together." (Carer 9)*

# 6.3 Summary and conclusions

The data suggests the more similar the experience of the Weaver to the Carer, the more successful the match seemed to be, including the achievement of outcomes. This would have to be further explored with a larger sample of Carers and Weavers where the outcomes for subgroups could be more effectively assessed.

The idea that the more similar the situation, the more quickly and easily a relationship is established and the more likely it would last beyond the formal relationship to allow the potential for further ongoing outcomes could also be explored in future research. Certainly, there is a suggestion, based on one Weaver-Carer match, that where there is a mismatch of one of the above factors (e.g. demographic factors such as gender), there is the potential for the relationship to falter and no outcomes to result and so this also should be further explored.

The main two outcomes achieved for Carers were increased assertiveness about their own needs and decreased depression (increased emotional wellbeing). There was evidence that the four pathways identified in the revised program theory were all at work in the program. These were helping the Carer to: navigate and negotiate the service maze; stay connected and involve others; work through the emotional challenges; and sustain things for themselves. Among the small number of survey respondents, Carers were more positive about having learned new skills or knowledge than having learned about or used new services.

Weavers identified outcomes including: a sense of purpose/meaning (for nine out of ten Weavers); increased confidence (four); social benefit (three); and reciprocity (two). Proposed mechanisms for these outcomes for Weavers include feeling valued for their role as a Carer, which they may not have been when a Carer themselves, and the recognition that they too would have appreciated such support during their caring role.

It is also possible that participation in the weaver network contributes to these outcomes. Situated learning theory (Lave and Wegner, 1990) suggests that learning experiences best occur in authentic contexts and that social interaction and collaboration are essential components in that. As learners become more involved in a “community of practice” which embodies certain beliefs and practices to be acquired, they may become more active and engaged in its culture, thereby moving to its centre. This suggests that Weavers learning ‘on the job’ in a social and collaborative context with other Weavers (e.g. through learning lunches) will become more expert in supporting Carers.

A small number of outcomes were also described for the person being cared for, such as increased use of services and more attentive caring by the Carer. The positive outcomes reported for Carers, such as decreased depression and stress, suggest Carers may be in a better position to manage their caring role in the longer-term which would be of benefit to the people they are caring for.

# 7 Future direction

## 7.1 Introduction

The interviews conducted with Promoters, the Local Connector, Carers and Weavers identify some suggestions for improvement and raise a number of issues of relevance to any future iteration of the program (or for other services providing support to Carers). The interviews and survey also propose areas of refinement for the way the program theory works in practice. These are outlined below, followed by recommendations for the future of the program.

# 7.2 Issues and suggestions identified in the evaluation

While the Weavers program has shown outcomes for a small group of Carers (and Weavers), it has been a challenge in establishment for the program to recruit and engage Weavers and Carers. This raises the question of what would need to be iterated and tested further in working towards program growth and making the concept scalable. The evaluation findings suggest ways in which these issues could be addressed.

## 7.2.1 Issues and suggestions identified by Promoters

Particular issues of relevance for the future of the program are identified by Promoters who had not referred to the program. The couple of Promoters who indicated they prefer to refer Carers elsewhere in the first instance may be unlikely to ever refer to the program since their views of where Carers should be directed initially may not be able to be changed. It was suggested this could be addressed through better alignment with existing services in the caring or aged care sector.

Promoters who had not referred to the program identified a number of factors that could be modified to increase their likelihood of referral, for instance, better promotion/increased awareness of the following features of the program:

- the age criteria (or broadening of the criteria);
- the program's model, approach and objectives;
- the Weavers themselves and the processes that ensure that Weavers are appropriate to the task, well-prepared and supported; and
- (where possible) the positive outcomes and feedback reported by Carers who have completed the program.

Aligning the program with a 'champion', was also a suggestion for improvement to the program.

## 7.2.2 Issues and suggestions identified by TACSI staff

New strategies have been developed to increase referrals of Carers. Examples which have shown some promise and could be considered in future iterations include the 'High Tea' for gaining interest directly from Carers and an approach to Promoters that follows up networking with a targeted event that involves the attendance of Weavers. Addressing the factors identified by Promoters (above) within the latter events could potentially improve referrals.

Current liaison with an existing organisation for a possible future iteration of the Weavers program creates a range of implications. Such an approach has the potential to increase access to Carers and, in turn, referrals. However, such a close connection with an organisation embedded in the aged care sector may influence factors that have been noted by Weavers and Carers alike to contribute to the success of the program, particularly the program's flexibility and adaptability as well as the perception that it is not a mainstream service. Future program design may need to address these issues.

## 7.2.3 Issues and suggestions identified by Carers

Some of the Carers who opted out did so because they no longer required the support. It is possible that for some, that this was provided by the Local Connector.

The example of the one Carer for whom there were no outcomes, demonstrated that the careful and considered process of matching is essential to the program's success and must not be circumvented.

The original objective of the program is long-term behaviour change, specifically equipping Carers with the tools they need to regain a sense of control and adopt new ways to manage the caring journey. The question has to be asked: does this program lead to long-term change? There is an indication of change of knowledge, attitudes and behaviour, and benefits to the Carers wellbeing, which can be seen in the outcomes and in the mechanisms through which outcomes are achieved. Whether these can be sustained in the long-term could not be assessed within the constraints of this evaluation and must be assessed in future iterations of the program.

A particular issue that should be addressed in any future iteration of the program is better clarity about the 'ending a match' process, which was raised by five Carers, specifically:

> *"We're two old people and we sit here every day and just look at one another. I can get over to shops and put his bell on, I just pop over to the shops and back again…but it's someone else to talk to for us…it's nice to have someone come and visit. It's better than me going out and not getting a visit*

> *as well. Because I haven't got any friends, we're too old, they've all died on me [it] makes you feel good...when you've had someone here to talk to... otherwise I start getting a bit depressed."*

Most of the Carers who had completed the program were happy with the service, to the point that they would refer others who were in a similar situation to the program. One Carer notes:

> *"If anybody came to me and said look...I'm trying to care for somebody and I don't know what I'm doing, I'd put them straight on to the Weavers. I wouldn't send them anywhere else because I've found the information out there is hard to get, it's confusing, there's nobody that can give it all to you. The people who are supposed to know what they are talking about...are not tuned in and these people that have been there are tuned in, they know what's required."*

However, some Carers identified issues that may need attention in the future. A particular issue that should be addressed in any future iteration of the program is better clarity about the 'ending up' process, which was raised by five Carers, specifically:

- Two hadn't realised that the formal match period had ended and responded with confusion to the suggestion that they had completed their time in the program;
- Two suggested they could have done with further/more formal contact with the Weaver and didn't quite know whether they could or should follow this up
- One Carer said they felt an expectation to have to continue with the match even though they'd got what they'd needed from it and didn't want any more involvement

Three Carers noted that sometimes being able to coordinate times and make contact with the Weaver proved difficult, but it usually worked out in the long run and so they were sufficiently satisfied. One Carer noted that some of the things the Weaver suggested were just not practical for her situation, but she was able to implement enough of them to make a difference.

This tension noted in section 6.2.4.1, between the provision of information and allowing the Carers to offload, and finding the right balance for each Weaver-Carer match, is pivotal to how the program functions and achieves its outcomes. It is important that this is taken into consideration in any future iterations of the program. It would also be beneficial to explore exactly how this works, and its influence on program theory, in any future evaluation.

### 7.2.4 Issues and suggestions identified by Weavers or the experience of Weavers

In any future iterations of the program, the factors that provide important context to the program's success, such as its flexibility and responsiveness to Carers and to Weavers, must also be maintained.

All of the support provided by the current program was considered to be useful in some way as part of a package of support. Weavers were most appreciative of the coordinator role and the support it provides, specifically selection, training and support to the Weavers, and helping them manage the relationship with Carers. If an existing caring organisation has the capacity to work more closely with this program in future and referrals were managed and maintained through their existing networks and structures rather than being the responsibility of the coordinator, this could have the benefit of maintaining the essential roles of the coordinator while reducing costs. Alternatively, perhaps, a volunteer Weaver or group of Weavers (who may have experience as a Carer as well as in the aged care or caring sector) could have more of a leadership role.

A major challenge to the program is identifying the best ways to recruit Weavers. Since many of the Carers willing to become Weavers also have professional experience in a relevant field (aged care or other caring sector), an important strategy for the future may be to target Carers who have worked in this field.

During the demonstration the pool of Weavers have taken on 2-3 matches at one time (original design assumed 1 match at a time). This shows promise for the cost-effectiveness of the program into the future.

Another possible strategy may be to maintain contact with Carers who have completed the program. Armed with a knowledge and appreciation of the program, they are at an increased likelihood of understanding the benefit of, and being interested in, the role. There has already been some interest from existing Carers about the possibility of becoming engaged in future. However, experience of other peer programs in human services sectors suggests that the proportion of Carers who will transition to become Weavers will be low.

# 7.3 Revised program theory

A major purpose of the evaluation is to determine whether and for whom the program achieves outcomes, what outcomes were achieved and how they were achieved.

In terms of context, the data suggests the more similar the experience of the Weaver to the Carer, the more successful the match seemed to be, including the achievement of outcomes. This, however, would have to be further explored with a larger sample of Carers and Weavers where the outcomes for subgroups could be more effectively assessed. The data confirmed that an appropriate duration of time is needed. This timeframe needs to be flexible and based on the needs of each individual match, so that it provides ‘enough’ time for that particular Carer-Weaver match.

Support for the Weaver-Carer matches being matched on a similar enough disability issue and a similar nature of relationship was identified, as per the original program theory. Additional contextual factors for the matches noted in the interviews were similar interests outside of caring and demographic factors (age, gender). The role of gender should be further explored in future evaluations (in matches by gender, and its role in the cognitive behavioural/paradox of choice mechanism). Other contextual factors that may contribute to outcomes in the program may be a high level of flexibility in the Carer-Weaver match, the Weavers having extensive experience and/or a professional background or knowledge in the caring and/or aged care sector, and the focus of the program and match being on Carer wellbeing (as opposed to trying to obtain outcomes for the person being cared for or the aged care sector). It also seems to work for people who identify themselves as being somewhat isolated and because Weavers does not work like ‘mainstream’ organisations.

The findings demonstrated support for a number of features of the existing program theory. The following anticipated outcomes were reported by Carers (and by Weavers for Carers) in this evaluation:

- reduced stress;
- reduced sense of isolation;
- reduced depression; and
- increased optimism.

An outcome identified through the evaluation, which was not in the original program theory was that Carers became more assertive about their needs. This could include taking more time out for themselves (as per the original theory), but was more often that they were doing more things for themselves; that they came to realise their own limits; or they took steps that prioritised their needs. Sometimes prioritising their own needs meant taking steps that better addressed the needs of the person being cared for, which in turn also addressed issues for the Carer.

Improved Carer wellbeing could potentially lead to improved outcomes for the person being cared for, if the Carer were able to provide better or more ongoing support for the person being cared for themselves or they initiated increased support and access to appropriate services. This evaluation was not able, given time and resource constraints, to examine whether medium and long-term anticipated outcomes were achieved and this remains an important question for future evaluation.

There was insufficient evidence that any Carers experienced increased self-efficacy in their Carer role, as was posited in the original program theory, but it is possible that some of the above outcomes may contribute to this outcome in the longer term. These outcomes may also enable these Carers to sustain their role over a longer period, but longer timelines would be required to evaluate such longer term outcomes.

There is evidence to support four of the mechanisms identified in the original program theory. These are that the Carer feels listened to and does not feel judged, which leads them – through social learning (described below) – to understand their rights and entitlements and feel validated and entitled to request support. Once Carers understood their rights and entitlements, and felt validated and entitled to use the supports and services in the service delivery system, this potentially shifted the power balance such that Carers were better able to navigate and negotiate, and were more likely to use, the available service delivery systems.

Social learning theory (Bandura, 1977) proposes that the people with whom one associates provides both models for and differential reinforcement of particular behaviours and attitudes. In this model, the "timing, length, frequency and nature of the contact" are important determinants of behaviour. For the Weavers program, it was originally posited that this might mean that Weavers act as models for positive behaviours by Carers, and reinforce Carers' existing positive behaviours. Further, it was proposed that because Carers develop positive relationships with Weavers and see the Weaver's experience as relevant to their own, they would be more likely to model their behaviours on those of the Weaver. Carer and Weaver interviews provided evidence that social learning worked as a mechanism in this program, specifically through role modelling and discussion of previous experiences on the part of the Weaver.

Two of the mechanisms were not well supported by the findings. Carers did not necessarily identify that they learnt strategies for the specific condition of the person being cared for or had a better understanding of the service delivery system. One Carer noted they had a changed perception of the condition of the person they were caring for which changed their attitude toward, and approach to, dealing with the condition.

The cognitive behavioural/paradox of choice mechanism is also proposed as a possible addition in any future refinements to the program theory, which could also be explored in future evaluations.

As proposed in the original program theory, there are indications of Carers requesting support from their wider social networks (such as family, for instance, using them for respite) and requesting increased services through the service delivery system (respite services, aged care homes). It is possible, as noted in the theory, that this could lead to improved quality of care for the person being cared for, but there is not enough evidence to be definitive about this in the current evaluation. Given the scope of the evaluation, no data was gathered on whether the program led to decreased use of emergency services, reduced the economic costs of health and the care system, or delayed entry to institutions. Due to the small number of Carers in the program, even if data had been gathered on these factors, the cost savings would have been likely to be minimal.

There was evidence for all four of the pathways identified in the revised program theory. These were helping the Carer to: navigate and negotiate the service maze; stay connected and involve others; work through the emotional challenges; and sustain things for themselves. The ways in which the Weavers model worked through the Adaptive Caring Loop, Narrative Approach and Ambiguous Loss to enable these pathways to work were also demonstrated.

# 7.4 Future directions / recommendations

The Weavers program has demonstrated that it is effective for the Carers who have been involved to date. However, it has not yet been able to demonstrate that it is a cost-effective way to provide support for a large enough group of Carers to have a substantial impact upon the aged care system. There is demand and a high level of satisfaction, but it needs to be tested further to assess the scale of impact..

TACSI has demonstrated that the Weavers program model can be effective in achieving outcomes for Carers (like increasing Carers' assertiveness about their needs and improving their emotional wellbeing) and for Weavers. Flexibility and responsiveness have been essential to this success. If the program is to continue, it should maintain the features that have been identified as important , take forward the learnings from this experience, find ways to increase recruitment and continue research and evaluation, including into its business model and program theory.

Based on the above we recommend the following:

- continue to explore models that draw from the direct and lived experience of those that are currently in the caring role and consider innovative and alternative options for Carers
- investigate whether Weavers can be purchased as a product through customer led funding such as Consumer Directed Care program and the new Integrated Carer Support Service (currently being designed)
- co-design (designing services in direct collaboration with consumers) approaches are to be applied to learn from community to better target services
- future projects consider recruitment a major component of research.

# 8 Appendices

# 8.1 References

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# 8.2 Literature review: Respite Care and its Effectiveness in Reducing Carer Burden

*Prepared by Katherine Radoslovich for Helping Hand Aged Care Research and Development Unit, December 2015*

## Summary

This report was repaired to investigate existing evidence on the effectiveness of different respite models on reducing carer burden.

Key findings

- Respite care is most commonly understood as referring to an extended on-site stay, day care programs, or regular in-home respite visits.
- Other programs aimed at reducing carer burden include psychological respite options such as carer social support interventions or programs to develop carer coping skills.
- There is limited evidence to support assumptions that respite has a significant or sustained impact on reducing carer burden.
- Where a benefit is evident, it is generally related to psychological, rather than physical, burdens of care
- There are a number of factors that shape carer decisions to use respite care services, including:
    - Anxiety over the provision of care by service providers
    - Guilt over leaving a person being cared for in respite care
    - Presence of meaningful activities of the person being cared for
    - Accessibility of services
- Respite Care is frequently identified as an under-utilised service, with variety of factors contributing to this. Under-utilisation may reduce potential benefits from respite care, as regular breaks have been identified as important to helping carers maintain non-care responsibilities.
- For respite care to be effective in mitigating carer burden, the following factors need to be considered:
    - Regular (e.g. weekly) in-home or day-care respite options provide carers with a chance to undertake household tasks, engage with social networks and undertake self-care, tasks which may otherwise be unachievable. This respite is important for long-term sustainability of at home care.
    - Carers require social support to make effective use of respite time. Service providers can assist in this through interventions or dialogue with carers over use of their respite time
    - Nursing staff can assist in reducing carer stress by engaging with carer's routines and knowledge of care for the individual concerned
    - Individualised and meaningful activities suited to the cared for person's abilities help reduce carer guilt over use of respite care

## Background

### Carer Burden

Informal carers are widely acknowledged at experiencing a collection of physical, psychological and social burdens. Skilbeck (2005)described care as "physically demanding and tiring," and argues that it can result in "stress, emotional worries, anxiety and things getting them [carers] down", bringing "more demands to juggle" and requiring continuous effort in "surveillance and monitoring the relative's condition." Building this idea, Conlin, Caranasos et al. (1992) state " the greatest burden experienced by caregivers is not being able to leave the house untended, and a major concern is the need to be relieved periodically from caregiving responsibilities". It is important to note, though, that caring is not only perceived as a burden by carers. Ashworth and Baker (2000) summarise the costs of caring as including "physical exhaustion, feelings of despair, lack of recognition and financial losses", while benefits include "a sense of closeness to the dependent and enhanced self-esteem." They also found that "psychological problems were more commonly reported than physical symptoms," particularly "an overwhelming feeling of despair." Respite care functions on the assumption that "relief from caregiving would enhance the caregiver's coping ability and hence prolong care at home" (Conlin, Caranasos et al. 1992).

Gilmour (2002)makes similar observations, with both Gilmour and Colin, Caranasos et al. arguing this is a simplistic understanding.

Since the 1980s, there have been a string of articles looking at the effectiveness of respite care options in reducing carer burden, particularly stress, and the cost-effectiveness of respite care. These articles generally conclude that the benefits of respite care are short lived if present at all, when specifically considering reduction of carer burden. Despite this, respite remains an important part of ageing with care in the home. Furthermore, adaptations of current respite models have the potential to significantly improve the effectiveness of respite care at reducing carer burden.

## Definition of respite Care

The Australian National Respite for Carers Program defines respite care as:

"Respite care is defined as an alternative or supplementary care arrangement with the primary purpose of giving the carer:

- a short-term break from the usual caring role; and/or
- assistance with performance of the caring role.
- Respite care is divided into direct respite services and indirect respite services, which are defined as follows:
- direct respite services provide the carer with quality alternative care for the person for whom he/she is the primary carer. Alternative care may be provided in the home, suitable temporary accommodation or an appropriate community setting; and
- indirect respite services provide the carer with assistance which relieves the carer of tasks other than the caring role, for example, provision of a shopping, gardening or cleaning service." (Australian National Audit Office 2005)

Within this definition, there are a wide range of ways that respite can be provided, and a variety of potential outcomes.

## Models of respite care

There are a variety of forms that respite care can appear in, including:

- In-home respite, including short and full day respite visits
- Out of home care, including day care programs and extended stays at care sites
- Support groups
- Carer education

All of these models in some way address fundamental objectives of respite, as identified by Neville, Beattie et al. (2014), in providing an opportunity for carer self-care, relief from the caring role, and safe alternative care for the cared for person. However, they also have different approaches in how they go about supporting carers, and there is a distinct lack of evidence over which options are more effective in reducing burden. In the search for evidence, researchers have taken different approaches. The following section will investigate these findings.

## Assessing the effectiveness of respite models on reducing curden of care

After an extensive literature review, Neville, Beattie et al. (2014) concluded that "it is challenging to predict which carers will benefit from respite and reasons why this may be so" because of the diversity of both research that has been undertaken and the vast range of people and types of services that have been reviewed. Barnett (2010) goes further in her critique of respite. In a 2010 report into a respite day care program prepared for the Department of Health and Ageing, Barnett concluded that:

"given the responsibility of caring for a frail older person or a person with dementia usually involves increasing levels of care, it is not surprising that the impact on carer health and well being is not large. It is perhaps unreasonable to expect that respite care could achieve such an outcome, as it is designed to provide a break from caregiving, not to change the underlying causes of carer stress or responsibility" - 9

This is not to say that respite is without purpose – just that it is challenging to absolutely reduce carer burden. Instead, it is part of a range of support and coping strategies. This section will review what is known.

## Is respite care effective at delaying residential aged care entry?

Evidence around whether respite care has the potential to delay residential aged care placements is both inconclusive and contradictory. Conlin, Caranasos et al. (1992) found that "the likelihood of institutionalisation increased nearly as often as it decreased" in response to use of respite care, with some carers using out-of-home respite care as a transition into care, while other carers' experiences of respite care resulted in a "realisation that adequate care could be provided by others". Meanwhile, Skilbeck (2005) noted that "some carers found it difficult to resume the caring role." Other studies found that some models of respite can assist in lengthening in-home care.Knapp, Iemmi et al. (2013) found that "counselling sessions and conversation groups resulted in significant delays in nursing home placements for people with dementia, compared to standard care arrangements" (i.e. care without intervention). Skilbeck (2005) noted that "a large proportion of carers often felt frustrated and angry with their relative. Traditional respite care once a year would do little or nothing to address these issues," instead recommending helping carers develop "problem solving strategies" and getting an "in-home break for a couple of hours a week" as more beneficial.

## Reducing stress and psychological impact of caregiving

As noted previously, psychological stress is a significant burden associated with care-giving. McConaghy and Caltabiano (2005) found that "higher levels of burden were associated with lover levels of psychological health", with higher demands for care associated with increased feelings of being overloaded or burdened, and noted that stress is related to greater risk of depression for carers. Respite care is hoped to reduce this aspect of burden, yet the evidence on its effectiveness is insubstantial. Skilbeck (2005) has noted that "there is an assumption that using respite care services will automatically reduce stress," but found that this was not the case. Indeed, respite admission processes and guilt over using respite services can be stressful in themselves.

There are a few studies that demonstrate a potential to significantly reduce carer stress through respite. Using the Relative's Stress Scale and Profile of Mood States to measure psychological well-being, Conlin, Caranasos et al.'s 1992 study "suggests that respite care for demented persons living at home significantly reduces the stress among caregivers." Specifically, they found that in-home respite services were particularly effective at reducing carer stress, as they directly addressed the issues of "restriction of social life and inability to leave the care receiver alone." Meanwhile, a Finnish study found that "periods of respite care had a major influence on informal carers' quality of life: 93% said they felt invigorated" (Salin, Kaunonen et al. 2009), although they note that carers need support from respite care nurses, focusing on well-being and coping strategies, to gain this benefit.

In opposition to this, a number of studies showed minimal change or a worsening of carer stress and/or psychological burden in response to respite care.Conlin, Caranasos et al. (1992) noted no impact of respite care on depression in caregivers, while Skilbeck (2005) noted that " there is little evidence to suggest that respite as an intervention in palliative care has a consistent or enduring beneficial effect on carers' wellbeing." Homer and Gilleard (1994) found that inpatient respite provided "no observable improvement in the carers' emotional well-being," and Flint (1995) found that "there was little evidence that formal respite care has a significant effect on caregivers' burden, psychiatric status or physical health."

## Getting on with Life

Despite inconsistent evidence around psychological carer burden reductions, respite does serve an important purpose in helping carers 'get on with life.' Researchers have consistently identified the importance of this opportunity, but have also noted that carers may require support to get the full benefits of such opportunities (see Supporting Carers). Skilbeck (2005) noted that carers found inpatient respite care important "as it allowed them to have a break and a rest from the ongoing care-giving responsibilities, as well as meet up with friends, go on holiday, spend more time with other family members." Yet, despite the opportunities for holidays, the most important of these was seen to be having time to "be able to do simple jobs that would be considered part of 'normal' life, but jobs that they were unable to do whilst caring for their relative." Ashworth and Baker (2000) similarly noted that respite "was important in bringing a sense of normality into the caring world" as it helped address feelings of "detachment from the real world" that many carers felt by allowing them to catch up on things they could not otherwise do. This was particularly effective when associated with regular respite breaks, and "home-sitting" was identified as a valued service.

## Physical burden

Little evidence was found to suggest that there are any reductions in the physical burdens of care through use of respite services.

Satisfaction without reduction of burden

Respite care provides benefits aside from reducing burden of care. Carers regularly express satisfaction with programs even without a reduction to their own stress. This is particularly evident where they feel the person cared for has received benefit from the program. Using satisfaction as a measure of the effectiveness of respite is thus not an accurate model of carer burden reductions, with Cox (1997) finding that "benefits in care-giver well-being were modest although satisfaction was high," while Nicoll, Ashworth et al. (2002) found that "carer satisfaction was not significantly correlated with carer strain nor depression." Meanwhile, Henry and Capitman in Neville, Beattie et al. (2014) found that "features of the carer and person with dementia were not useful in predicting satisfaction with respite, and suggested that characteristics of the respite service itself may be more influential."

## Reasons for not using care

There are a number of reasons that carers may decide not to utilise respite services. van Excel, de Graff et al. (2007) argue that in fact there are "three distinct groups of caregivers: informal caregivers who need and ask for respite care, those who need but won't ask for respite care, and those that do not need respite care", and that respite care programs should be targeted at the first two categories. The impact of non-use by those who need it is, as Cox (1997) argues, that the effectiveness of respite care "remains compromised due to the frequent resistance of caregivers to actually utilise services." The reasons for non-use of services has been the topic of a number of studies, with factors including recognition of need, knowledge of services, trust in service providers and self-permission repeatedly appearing.

Neville, Beattie et al. (2014) report one explanation of non-use:

"Strang and Haughey (1998) proposed that accepting and obtaining respite services involved three steps for the carer: 1. Recognising the need to get out of the carer world, 2. Giving themselves permission to leave it temporarily, 3. Having the availability of social support resources to facilitate 'getting out'."

This model is reflective of a number of other studies. Neville, Beattie et al.'s own work found that "carers often assert that help is not needed" and do not give themselves "self-permission to utilise respite." Phillipson, Jones et al. (2014) have noted that the carer's own beliefs about care, as well as their perceptions of services and service providers, are likely to shape whether they use respite services, which matches van Excel, de Graff et al. (2007) findings. For carers where there is a reluctance to use respite care, van Excel, de Graff et al.'s argue that "effort should be directed to both caregiver and care recipient" to convince both "that it is in their mutual interest to make the care giving task manageable in the long run" because their evidence suggests that those who need but will not ask for respite care "report serious burden from care-giving". Their assumption is that respite care will reduce carer burden. In addition to this, though, there is also an element of social situation involved in influencing uptake. Phillipson, Jones et al. (2014) found that stigma may "influence a preference for in-home respite services for some carers," particularly where the is embarrassment at taking the care recipient in public, while Ashworth and Baker (2000) note that for many carers "accepting respite care was frequently seen as an admission of failure." In spite of these negatives, Phillipson, Jones et al. note that "carer beliefs that services were high utility, high quality, or were trustworthy were associated with respite use." So they key to uptake of respite services seems to revolve around improving carer and care recipient knowledge of respite opportunities and supporting them to identify their potential utility and appeal.

A number of commentators have also noted that demographic details can impact on respite uptake. In their Australia, Neville, Beattie et al. (2014) found specifically that "uptake by carers of people with dementia remains relatively low." Meanwhile,DeCaporale, Mensie et al. (2013) found that adult children are more likely to use respite care in response to high rates of grief, including anticipatory grief, while grief was seen to have no impact on spouse carers uptake. On the whole, Phillipson, Jones et al. (2014) found that spousal carers were less likely to use "day centres" or "respite or other carer assistance." They also found that female carers were less likely to use specialist in-home services, while carers aged over 70 were less likely to use non-specialist in-home services. Ivey, Laditka et al. (2013) and Phillipson, Jones et al. have also noted that ethnicity and culturally-based views can impact on both the experience of caregiving and the uptake of respite services. In the face of this diversity, Phillipson, Jones et al.'s recommendation to set up "sub programmes at the community level that target particular groups of carers.... who may be prone to non-use of specific types of respite services" makes a lot of sense.

## Factors for making respite care more effective at reducing carer burden

### Accessibility

A number of commentators, including Conlin, Caranasos et al. (1992), Phillipson, Jones et al. (2014) and Ashworth and Baker (2000), have noted that the process of getting a cared-for person ready for and to and from a respite program, whether a day care or multiple-day stay, can be stressful and "a burden in itself" (Ashworth and Baker 2000). Furthermore, carers need access to services (e.g. local, with reasonable waiting times, accessible online or at home) and "must have the knowledge or the 'know-how' as well as the resources (such as health insurance or adequate income) to enable them to use services" (Phillipson, Jones et al. 2014). Service providers should consider this when designing programs.

### Building relationships with respite staff, utilising carer knowledge

As has been noted, a number of carers find trusting respite services with responsibility for the person they care for a cause of additional stress. Particular issues of concern include the quality of care that will be received and changes to routines they have established. Skilbeck (2005) notes that there is a desire from many carers for more detailed information about respite services they plan to utilise and how the respite program can be adjusted to meet the needs of the person being cared for. Familiarity with routines and care provision expectations also helped reassure carers that their cared-for person was in safe hands. This knowledge was found to help reduce distress at the use of respite services.

In addition to having enough knowledge of services, carers have also indicated a desire to have some control over how respite care is delivered. For example, Neville, Beattie et al. (2014) found that some carers want a say in "which staff provide care during respite." Skilbeck (2005) observed that many carers desire a "continuity of care," meaning they desired home routines to be followed. Gilmour (2002) argues that nurse-family relationships are vitally important to the success of respite in reducing carer stress, as the approach nurses takes to engagement with primary carers can "ameliorate" or "exacerbate" the tensions that carers feel over utilising respite care. In particular, she argues that nurses need to "acknowledge the family caregivers as the primary caregiver" and utilise their knowledge of the person to "inform care within the institutional setting." In particular, it is important for respite care to attempt "to follow the home pattern of caregiving", and to "preserve preadmission levels of functioning," to assist the transition back to home care after respite, and to relieve tension of carers by acknowledging their knowledge. To facilitate this, admission processes need to include adequate time for primary carers to meet with key nursing staff to discuss how care will take place.

## Purpose within program

A number of studies have found that the provision of activities that are meaningful and suited to the capacity of the person cared for helps reduce carer burden, by reducing carer guilt about using the services. For example,Neville, Beattie et al. (2014) found that "when using institutional respite (whether for the day or for an extended period), carers have shown a preference for respite that has social or recreational activities enjoyed by the person with dementia and that are age-appropriate." Meanwhile a German study found that in social care groups "people with lower cognitive function are excluded from most activities" (Hochgraeber, Riesner et al. 2013), creating a potential for carer guilt over leaving the cared for person in a situation of exclusion. A number of respite programs have been trialled that demonstrate effective ways of providing individualised, purposeful respite that carers engaged positively with.

Side by Side, run by Life Care, was a workplace engagement project for people with Early Onset Dementia that placed individuals in a hardware store in a supported program over the course of six weeks. This respite model is noteworthy because it was well-received by carers and participants. Carers described it as "guilt-free respite", because the program was considered meaningful and to have a positive impact at the time. According to Robertson, Evans et al. (2013) "family carers reported that participants are more mentally alert, have improved self-esteem and exhibit a greater interest in life in general as a result of their engagement in the program." These improvements were not a lasting change, but carers suggested "that 'you do it for the moment'; that an activity is worthwhile even if it gives benefit only while it is running."

The Tailored Activity Program reported on by Jutkowitz, Gitlin et al. (2010) was an "8-session, 4-month structured occupation therapy intervention" that "provides dementia patients with activities tailored to their capabilities, and trains family caregivers in their use." The program was designed to reduce carer burden by improving functionality of the participants. As reported,

"based on this assessment, therapists develop activities to match patient interests and capabilities and then instruct caregivers in their use, including how to set up the environment, introduce and supervise the activity, and communicate and cue effectively…. It also benefited caregivers by enhancing their sense of confidence using activities in daily routines and reducing the time required in daily oversight or vigilance."

This program aims to have lasting results, but it is unclear how long-term they were.

Holm and Ziguras (2003) reflect on the Australian federally-funded "host-homes program" as an alternative model of respite care. This program was established by the Brotherhood of St Lawrence, providing respite care to people with dementia in a care-worker's home. The program allowed up to 6 people with dementia to spend 6 hours doing activities in the home of a care-worker, and included pick up and drip off of the participants. This program was apparently positively received by carers who valued the more personalised approach of the program, the enjoyment the participants had, the "homely" feel of the program, and the break they got to do other things. However, for this model to be effective on a larger scale, they emphasise the need for Federal Government guidelines to "avoid potential cost-shifting and to encourage high quality care".

## Supporting carers

The final factor to be discussed in regards to utilising respite care to reduce carer burden relates to supporting carers to make the best use of respite time and develop rounded coping strategies. A number of studies have specifically called for social support interventions to assist carers. McNally, Ben-Shlomo et al. (1999) found that there is "little evidence that respite intervention has either a consistent or enduring beneficial effect on carers' well-being", which they attribute at least partially to the fact that "respite care often fails to facilitate the maintenance of social supportive relations, which may moderate strain after respite has ended." In response to this, they advocate a more "carer-centred" approach to respite, specifically by supporting carers through “interventions to facilitate social contacts and relationships”. Meanwhile, Neville, Beattie et al. (2014) found that “the amount of time provided by respite may not be as important as what the carer did with their respite time and the satisfaction these activities brought them.” They recommend “that facilitators should be employed to work individually with carers to identify activities and goals for respite time that are most likely to improve their well-being.” Similarly, in their study Nicoll, Ashworth et al. (2002) identify social support of carers as a significant factor in determining carer satisfaction with respite, and specifically found that “more important than the roles taken by those supporting the carer was the number of those available to provide support.” They outright state that “successful respite care may only occur when the carer has a support network which enables them to re-establish social contacts and to enjoy other social roles than that of the permanent carer.”

Supporting carers likely requires active intervention on the part of service providers. This may be a social support program, or it could be achieved through nursing staff engagement, as discussed previously. Some trials into carer support have occurred.Drentea, Clay et al. (2006) look at the results of an experimental social support intervention for Alzheimer’s carers, concluding that counselling and social intervention were effective at helping strengthen both the carer’s social support structures and carer social support satisfaction. Furthermore, visits from the carer’s support network provided a chance to socialise, which Drentea, Clay et al. describe as providing a form of “psychological respite in their homes.”

A number of studies have looked at other interventions that might assist carers in better utilising their respite time and building enduring skills to reduce burden after respite finishes. Whitebird, Kreitzer et al. (2011) identified the potential for “complementary therapies such as mindfulness-based stress reduction” to assist caregivers experiencing chronic long-term stress, but at this stage there is a lack of clinical evidence to support or reject this claim. McConaghy and Caltabiano (2005) argue that supporting older people to develop “active coping strategies” such as “more effective care techniques” was more effective than “emotional focused strategies” as it can help reduce the source of stress. And finally,Rabinowitz, Saenz et al. (2011) have found that care-giver self-efficacy has a significant impact in mediating depressive symptoms for carers, and that interventions designed to build these skills could be useful in supporting carers and reducing burden. They define care-giving self-efficacy as “a caregiver’s beliefs about his or her ability to negotiate the stressors and challenges inherent in the caregiving process.”

Overall, it is clear that actively supporting carers to use their respite time, and build skills during respite, is important to its success in reducing burdens of care.

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# 8.3 **Realist Evaluation**

Realist Evaluation (Pawson and Tilley, 1997) starts from different assumptions than other evaluation approaches[9]. Many evaluation approaches operate as though programs are 'active' and that the participants who take part in them are 'passive'. That is, the assumption is that if the program is 'right', it will 'work' regardless of the situation. Another basic assumption is that 'the program' is the same, and will be implemented in the same way, everywhere it is implemented.

Realist Evaluation turns this around. It assumes that programs provide resources of various kinds, but that participants are active decision-makers who respond in different ways to the resources on offer. The basic ideas in a realist evaluation are as follows:

- Programs work by enabling participants to make different choices (although choice-making is always constrained by participants' various experiences, beliefs and attitudes, opportunities and access to resources).
- Making and sustaining different choices requires a change in participant's reasoning (e.g. values, beliefs, attitudes, or the logic they apply to a particular situation) and/or the resources (e.g. information, skills, material resources, support) they have available to them. This combination of 'reasoning and resources' is what enables the program to work and is known as a program 'mechanism'.
- Programs work in different ways for different people (that is, programs can trigger different change mechanisms for different participants).
- The contexts in which programs operate make a difference to the outcomes they achieve. Program contexts include features such as organisational context, program participants, staffing, geographical and historical context, and so on.
- One of the tasks of evaluation is to learn more about 'what works for whom', in which contexts particular programs do and don't work, and how programs work (that is, what the mechanisms of change are).

Whenever a program is implemented, it is testing a theory about what 'might cause change', even though that theory might not be explicit. One of the tasks of a realist evaluation is therefore to make the theory in a program explicit, by developing clear hypotheses how, and for whom, programs might 'work'. Data collected through the evaluation is used to refine the program theory. The refined theory can then be used to improve the program design, to decide whether a new program is suitable for a new context, or to adapt the program for new contexts.

A realist evaluation approach was considered appropriate for the Weavers program because:

- The program is innovative and its theory of change has not been tested before. A realist approach allows for exploration of the kinds of outcomes that are achieved (if any) and what it is about the program model, and the circumstances of those involved, that supports change.
- It allows for comparison of processes and outcomes within the program, among different subgroups. However, this aspect will only be possible in future research, due to the small sample of participants available in the present evaluation.
- It can be applied without requirement for a comparison group.

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*[9] This description of the methodology was first used in the evaluation of TACSI's Family by Family Program (2012 evaluation report).*

# 8.4 **Narrative of interview process**

1. **Local Connector records and interview**
   In July 2015, the Local Connector of the Weavers program provided a list of Promoters who had been approached to provide referrals to the program, or with whom the Weavers program had begun liaison. The Local Connector provided contact information for Weavers and carers and responded to any ongoing queries of the evaluation team. A formal interview was held with the Local Connector in February 2016, about the functioning of the program and the key evaluation questions. Additional administrative program data, particularly on recruitment numbers, was provided by TACSI in February-March 2016.

2. **Promoter interviews**
   Ten face to face interviews were held during October 2015 with a sample of Promoters who had sometime prior to that been approached by Weavers program staff to provide referrals. These Promoters came from two different categories: those who had referred to the program; and those who had not. Since recruitment numbers were quite low at the time of these interviews and there were only five Promoters who had referred to the program, there seemed to be no purpose in differentiating between ‘hot’ referrers (those who had referred to the program more than once) and those who had referred ‘once off’, as per the evaluation design. The main purpose of these interviews was to explore who does and does not become a referral point for the program and their reasons why. Promoters were also asked about their perceptions of the service and the support it provides carers, which elicited discussion about its role within the aged care system. Of the 10 interviews with Promoters, five of these had already referred a carer or Weaver to the program at the time of interview and five had not.

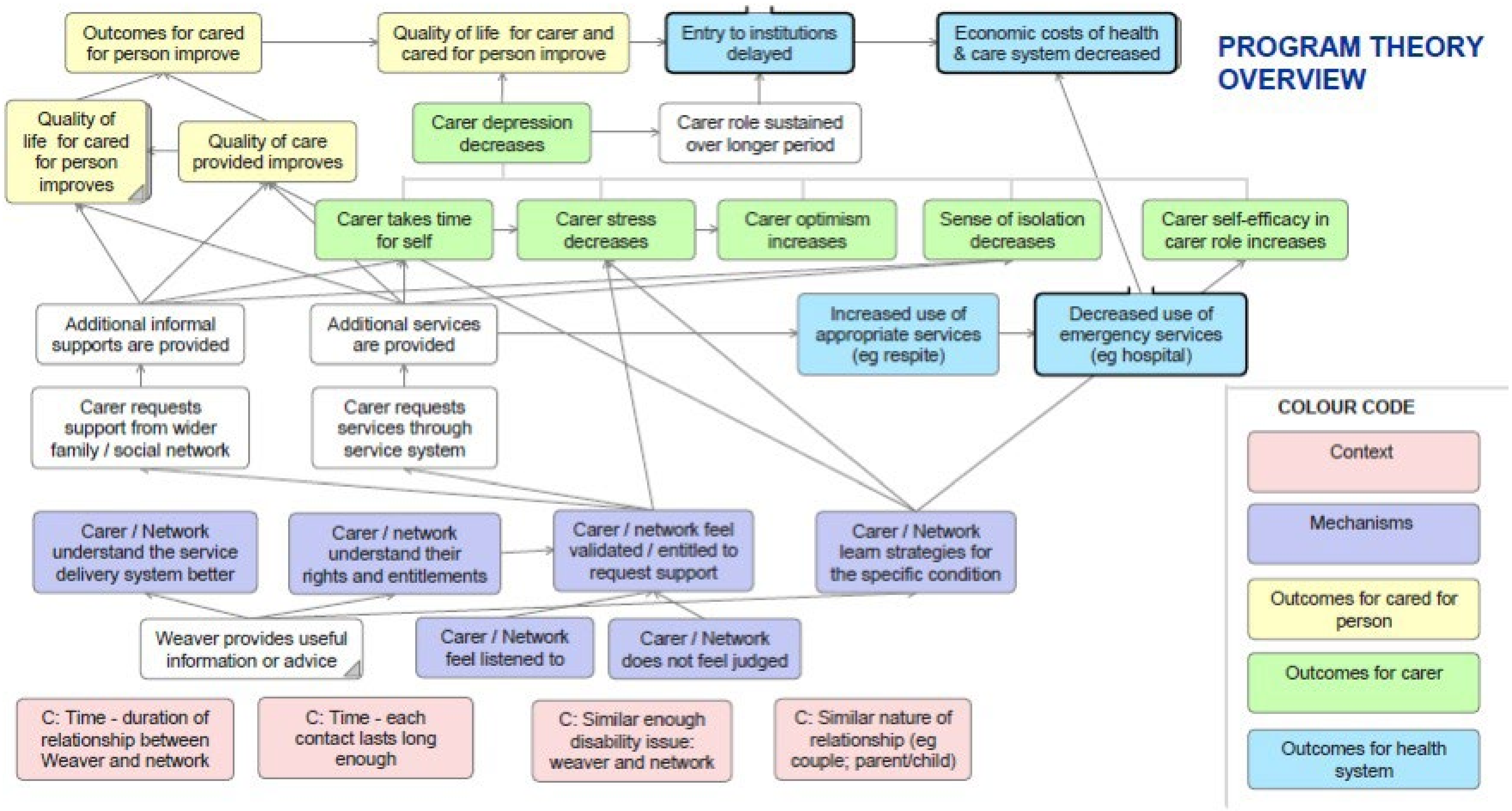
3. **Interviews with carers who opted out of the program**
   Interviews were held over the phone during October 2015 with 6 carers who opted out of the program, the purpose of which was mainly to ascertain their self-reported reasons for not participating in the program. An additional 3 carers who, at that time, fit the same criteria, were deemed unsuitable for interview because of their personal circumstances (e.g. recent bereavement) after either phone contact with the Carer or a discussion with TACSI. At the time these interviews were held, those who opted out represented approximately one-quarter of referrals

4. **Interviews with carers who completed a match in the program**
   During December 2015 through to early February 2016, 13 phone interviews were conducted with carers who the Local Connector considered to have completed their match and hence were identified as suitable for interview (three males and 10 females). These were all of the carers considered eligible. All had completed at least a 12 week period in a match with a Weaver. Carers were asked about their experience of the program, their perception of how successful the match with a Weaver was for them, as well as any outcomes they attributed to the program. Although the Local Connector’s records defined them as complete, a couple of carers were uncertain about whether they had formally completed the program. This is an issue that should be further explored. Carers in their interviews were asked about the use and benefit of any support tools, how what the program or the Weaver did might have led to any outcomes, and any suggested changes to the program.

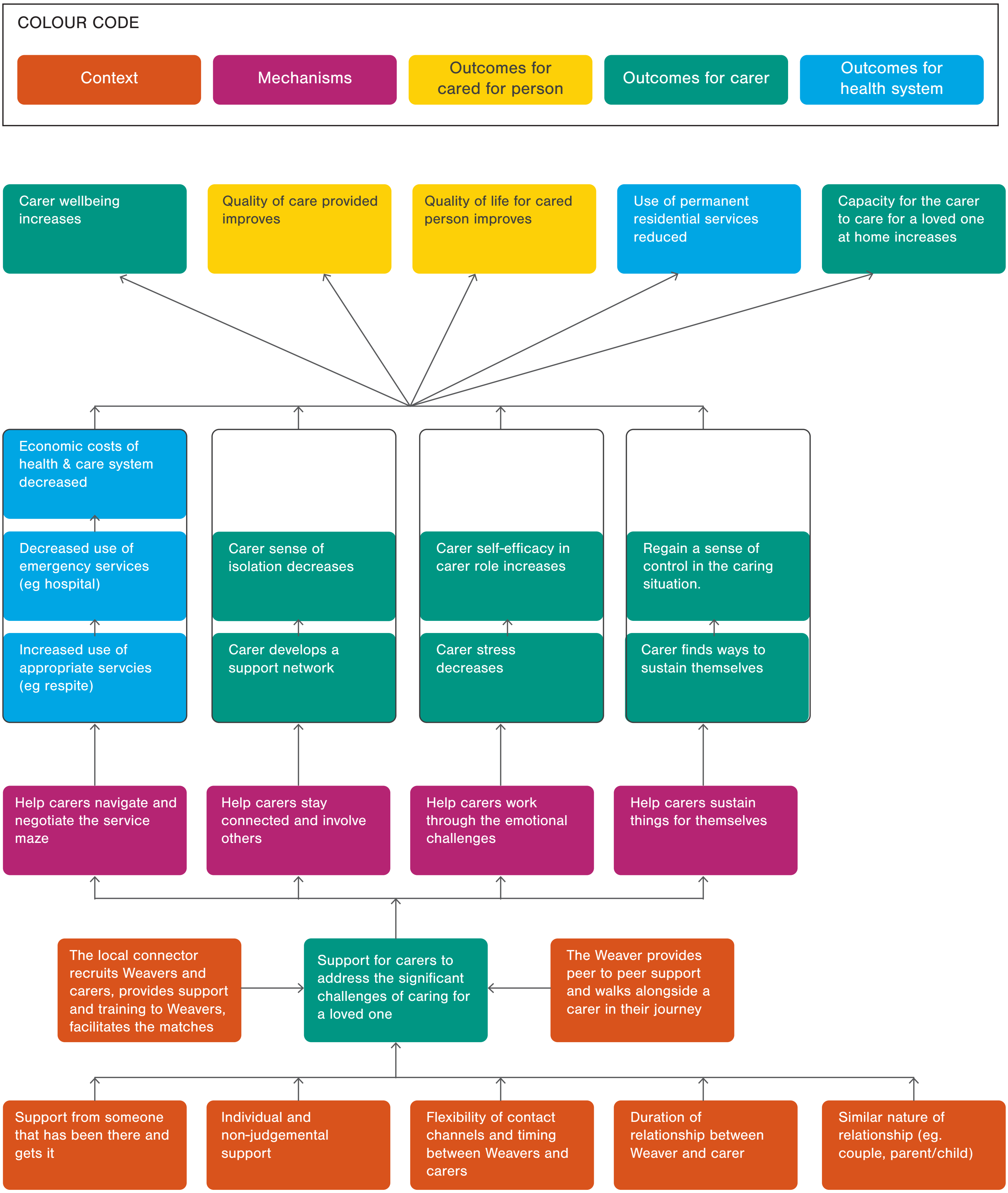
5. **Weaver interviews and focus group**
   Ten interviews were conducted with Weavers: three males, six females and one male-female couple. Nine were held face-to-face, while one Weaver who was interstate was interviewed by phone. Three 'Weavers' (four individuals due to the husband and wife team being counted as one 'Weaver') were interviewed in August 2015 and these three Weavers also participated in a focus group about the supports they received. Due to timing and logistical difficulties in arranging the remaining volunteer Weavers to come together as a group at later learning lunches as planned, this was the only focus group held. Another three Weavers were interviewed in late November/early December 2015 and the final four in January 2016. These Weavers were those deemed by the Local Connector at that time to be suitable for interview. It was expected that these would be those in a completed match with a carer. All Weavers eligible (identified by the Local Connector) were interviewed. However, two Weavers interviewed did not have corresponding 'completed' carers who were interviewed, their carers were instead 'fairly progressed' or close to finishing. These carers had at least completed 12 weeks in the program and shown some outcomes and so these Weavers were included. As Weavers often had experience of more than one match, they were asked about their perception of what factors contribute to successful matches. They were asked about their own outcomes as well as any outcomes for carers that they attributed to the program, including their perception of how they or the program might have contributed to any outcomes. The use and benefit of any support tools was explored and they were also asked about suggested changes to the program.

An interview was also held in March 2016 with another TACSI staff member who had a significant role in the development of the program and in the future directions of the program. This interview was intended to provide additional information about the program's history, development, and its strategic aims, including future options being explored for its growth and scaling within the aged care sector.

# 8.5 Original program theory



# *Updated program theory*



COLOUR CODE

- Context
- Mechanisms
- Outcomes for cared for person
- Outcomes for carer
- Outcomes for health system

Carer wellbeing increases

Quality of care provided improves

Quality of life for cared person improves

Use of permanent residential services reduced

Capacity for the carer to care for a loved one at home increases

Economic costs of health & care system decreased

Decreased use of emergency services (eg hospital)

Increased use of appropriate servcies (eg respite)

Carer sense of isolation decreases

Carer develops a support network

Carer self-efficacy in carer role increases

Carer stress decreases

Regain a sense of control in the caring situation.

Carer finds ways to sustain themselves

Help carers navigate and negotiate the service maze

Help carers stay connected and involve others

Help carers work through the emotional challenges

Help carers sustain things for themselves

The local connector recruits Weavers and carers, provides support and training to Weavers, facilitates the matches

Support for carers to address the significant challenges of caring for a loved one

The Weaver provides peer to peer support and walks alongside a carer in their journey

Support from someone that has been there and gets it

Individual and non-judgemental support

Flexibility of contact channels and timing between Weavers and carers

Duration of relationship between Weaver and carer

Similar nature of relationship (eg. couple, parent/child)

# 8.6 Narrative of Weavers operational model

The program has been managed by TACSI and implemented in the following way:

- One paid 'Local Connector' has been specifically allocated to the program. Their role involved encouraging referrals from Promoters, managing the website, recruiting Carers and Weavers, facilitating matches between Weavers and Carers, and providing training, monitoring and support for Weavers in their own development, personal situations and caring role. Other TACSI staff have supported the program on an as needed basis.
- Carers, including those who wish to become a Weaver, can either self-refer to the program or be referred by services or others. Although the eligibility criteria have not been widely publicised, and no constraint has been placed on age of the Carer themselves, the person they are caring for is expected to be over 55. While no disease type has been specified, the care recipient is expected to have a 'condition of ageing' which could be cognitive and/or physical.
- To generate referrals through the demonstration research period, the Local Connector raised awareness of the program in various ways. Organisations in contact with Carers were targeted and these were called 'Promoters'. Initially organisations that provided support to Carers were directly and individually approached for referrals. The TACSI website and flyers also advertised the service. The focus of the program was initially in Northern Adelaide, however, in practice, to gain adequate numbers and follow the need, Carers and Weavers were later recruited from all over the Adelaide metropolitan area. The ways these organisations and Carers themselves are approached have changed over time, based upon what has been learnt as the most proactive ways of engaging with Carers. A more recent focus has been on creating opportunities to have valuable conversations with Carers in various contexts that enable TACSI to share the benefit of matching with a Weaver and the unique type of support offered by the program. The Local Connector has networked with organisations connected to Carers for the purpose of developing a referral pathway and has also attended community events that engage specifically with Carers to promote the program. More recently, the Local Connector has been holding specific events to which potential and existing Promoters are invited, at which Weavers have often also been present.
- People who have had a lived experience of caring and show interested in becoming a Weaver are interviewed by the Local Connector to identify whether they are suitable for the program. Carers considered for the role of Weaver must be able to demonstrate that they are emotionally ready to support others in managing the burden of the caring experience, although they do receive some support from the Local Connector to work through any issues this may raise for them. A particular characteristic that may benefit Carers in undertaking the role, and which a number of Weavers do have, is previous work experience in the aged care or other caring sector. Weavers selected for the program undergo orientation training (particularly in adaptive caring, narrative approaches and ambiguous loss, as mentioned in the previous section) and receive ongoing professional development and case management. In practice (in contrast to the original design), Weavers can have multiple matches, the number of which at any one time is determined only by the capacity of the Weaver themselves.
- Professional development is provided to the Weaver via regular Weaver 'Learning Lunches', held monthly. These may include external speakers and discussion, with other Weavers and the Local Connector, of cases or issues that have arisen. This capacity to learn from other Carers and their experiences is important in the peer-to-peer model.
- The formal stage of interaction between a Weaver and a Carer is known as a 'match'. Carers who agree to participate in the program and be matched with a Weaver meet first with the Local Connector who assesses their story and situation. At this stage, the Local Connector also identifies, in discussion with the Carer, factors to be addressed in the match. The Local Connector then identifies a few suitable Weavers for them to be matched up with, based on criteria such as: the condition of the person being cared for, and the type of relationship between the Carer and the person being cared for (e.g. partner or child-parent). The Carer chooses one from these options.
- Weavers and Carers both receive information about the possible match through a profile which is prepared by the Local Connector based upon the Local Connector's first meeting with the Carer. The Carer and Weaver must choose/agree to the match before a meeting is arranged.

- The Local Connector is present at the first meeting between the Weaver and Carer. This ensures a smooth introduction to the program and enables all participants to be clear about the Carer's needs. The Weavers discussed in their interviews how this approach (compared to the prototyping phase in which only the Weaver and Carer were present at the first meeting) provided better support to the Weaver, which is further explored in section 2.2.
- The nature of contact throughout the match is agreed and negotiated between the Weaver and the Carer, depending on their personal circumstances. During the formal period of the match, the Weaver focuses on the factors identified to be addressed at the first meeting. These could include, for example, how to better manage things for themselves or how to navigate services and create stronger connections. Some contact during matches will be held face-to-face over a coffee, while others may include a combination of various methods such as phone calls, texts and emails.
- Weavers are expected to provide reports to the Local Connector on the progress of their matches. Feedback should usually occur via the 'Loom' or at the monthly Learning Lunches. The Loom is a website developed for Weavers for the purpose of liaison with the Local Connector and to seek advice and input from other Weavers on particular issues. Learning Lunches are a critical part of the reflective feedback process. If, however, there are ongoing or unexpected issues that require timely discussion, or technical or other issues prove to be a barrier, these updates may also be reported directly to the Local Connector via phone or in person.
- Ideally, a meeting will be arranged with all parties (Weaver, Carer and Local Connector) after a minimum period of time in a match, to evaluate the progress of the match and reflect on what the Carer is now able to draw upon for support. If appropriate, ending the formal relationship between the Weaver and their Carer may be discussed. Initially this was scheduled around 12 weeks after commencement of the match, but is now more likely to be after a 15-20 week period (because it became clear that 12 weeks was not always sufficient to complete the focus areas, and also depended on the level of support required). If after the 15 week period the Carer feels they need further support, then the match is extended to ensure that Carers are equipped with the tools and supports they will need. If they feel capable of continuing their caring journey without the support of a Weaver, the formal match will come to an end, although Weavers and Carers may choose to continue an informal relationship.
- To protect confidentiality, Promoters are not specifically kept informed of how the Carer is progressing in the program, except perhaps to confirm whether or not they have engaged in the program.
- It is important to note that early in the design of the program it was intended that Weavers would also work with the Carers' network (their family, friends, and so on). To avoid conflicts of interest, it was decided that the Weaver would not work with the Carers' support network but may instead support the Carer to extend or make better use of their support network.

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