



**Department of Social Services  
Designing the new integrated carer support service –  
a draft service concept for the delivery of interventions to  
improve outcomes for carers**

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**Submission, June 2016**

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## Who we are

The Australian Centre for Social Innovation (TACSI) exists to develop, test and spread innovations that change lives for the people who need it most. At the heart of TACSI lies the fundamental belief that people are the experts in their own lives. We believe that the best innovations come from working alongside the people who face the very challenges we're trying to solve.

TACSI is based in Adelaide but works all over Australia, both on our own programs and with a range of businesses, NGO's and government organisations in a range of different sectors and contexts. TACSI help them develop, test and spread effective innovations in practice, in services, in systems and policy. We build the capability of organisations to find opportunities, design, trial and spread solutions.

## Principles of our approach

### *We start with people*

We believe effective social innovation can only come from prioritising what people want and need over what systems want. We put this into practice by using a co-design approach – we work with people to design policies, programs and solutions that work for them. We specialise in designing with hard to reach and vulnerable groups.

### *We use diversity*

Getting to better solutions requires different thinking. We believe that no one discipline has the monopoly on social innovation. Our core methods are drawn from design, business innovation, and the social sciences – but we draw on community development and international development too. Some of our people come from an innovation background, some from a practice background, all are united in their passion for impact.

### *We're serious about impact*

Our role in Australia is to find new ways to address tough social challenges. We continually ask ourselves 'Is this leading to change?' and expect the same from our partners.

### *We learn through doing*

Our approach is grounded in our own experience as an NGO developing, testing, and spreading new programs for families and carers. We dedicate significant time to learning and continually improving our own practice.

## Our work in Caring

Our first project began in 2011 with the challenge: as our population ages, how can we improve outcomes for older people in caring roles and relationships? The project brought together SA's Office of the Ageing, the cities of Salisbury and Unley, Helping Hand and ACH Group. We met and spent time with over 130 people in caring roles and relationships in a range of ways, in different settings and utilizing different tools - structured interviews using a detailed topic guide inspired by research and recruitment conversations; visual tools to make abstract ideas richer and more concrete; and ethnography topic guides that focused on observation of people,

behavior and environment. On top of this, we acted as a fly on the wall to various services within the ageing and caring space, observing, experiencing and understanding.

From this user insight research, we co-designed 6 new solutions in ageing and caring that aim to build the resources that enable great living in late adulthood. One of these solutions was Weavers. Weavers is a peer-to-peer model supporting carers to address the significant challenges of caring for a loved one. Weaver volunteers are people with lived caring experience; they truly understand what it's like, and are trained to use this know-how to support carers in their local community. Weavers is built by carers and strengthened by evidenced-based practices. It draws on the untapped community resource of experienced carers, provides individualised support to carers at very low cost, and addresses gaps in the ageing sector which is struggling to meet increasing demands. Following the co-design phase, TACSI has continued to run a larger scale demonstration and evaluation of Weavers in metropolitan Adelaide until June 30<sup>th</sup> 2016. Independent evaluation has identified that through the support of a Weaver, the following outcomes have been reported;

- Increased assertiveness about own needs
- Less stressed
- Increased optimism
- Decreased sense of isolation
- Decreased depression

### Feedback on the draft service concept

This document provides feedback for TACSI, as requested within the consultation phase of the DSS 'Designing the new integrated carer support service – draft Service Concept' document. Our response to the document is based on a combination of our expertise and experience in co-design process, methodologies and tools such as ethnographic research and co-creation workshops; as well as service delivery experiences. We have broken our feedback down into the following two sections;

- Structured responses to 'Part B proposes the supports that could be delivered by a new integrated carer support service'
- Design progression questions and feedback

### Structured responses

Awareness	
<p><b>What would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?</b></p>	<p>TACSI agrees with the overall objective of awareness to find Carers and in particular hidden carers and encourage them to make use of available interventions.</p> <p>Through co-design, we were also able to establish that as stated in the paper, health care settings are an ideal point of referral and that networking with services that are already involved in providing support or services is one way of connecting with carers in the early stages. However we also understand that it is much more nuanced; we identified that the people in the</p>

	<p>healthcare setting who would make the referrals form part of a 'Promotor network' for carers. Promoters have a trusted relationship with the Carer such as a GP, physiotherapist, pharmacist, hospital Social Worker or even the hairdresser. It then becomes more than just handing over a brochure of information about a service but an interaction where these promoters have engaged with the Carer in relation to a recent diagnosis, some new symptoms, the experience of challenging behaviours, not being able to sleep or feeling overwhelmed. Due to this relationship, the Carer is then more likely to access the service.</p> <p>In addition to this we also know that 4.1 million employed people in Australia (38.2% of all employees), have unpaid caring responsibilities with this number to grow substantially over the coming decades (AHRC, 2013). Given this, how can we equip workplaces to support their employees to access services early in their caring journey. TACSI has done some initial research and planning on this.</p>
<p><b>Should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than in schools?</b></p>	<p>TACSI's service delivery work has focussed on ageing and caring rather than young carers. Other services would be in the best position to respond to this question.</p>

<p><b>Information provision</b></p>	
<p><b>While information is available through carer organisations today, as well as the Carer Gateway, would individualised recommendations be of benefit when carers are undertaking or receiving other services?</b></p>	<p>At TACSI, we found that having individualised or tailored support for Carers that is relevant to their stage of the caring journey is essential to reduce information 'overload' and people actually engaging with a service. Not dissimilar to findings from your co-design workshops, Weavers narrowed these down into four main areas; navigating and negotiating services, connecting with family and friends, sustaining things for themselves, and managing emotional challenges. Through these areas, Carers can then be supported to think about what it is that is right for them and their family in relation to where they are at in their caring journey.</p>

<p><b>Intake</b></p>	
<p><b>Are there ways to make intake a more beneficial process for carers? When should intake be a mandatory process?</b></p>	<p>The importance of connecting carers to the right supports and services that are needed in a caring situation are clear. In an intake process, even though Carers don't receive service provision, it is important that they still receive 'a next step'. If intake is not critical to eligibility and funding then timely</p>

	community based responses should be enabled rather than Carers having to go through a mandatory intake process. Here at TACSI through user insight we have an understanding of the challenges people have faced in getting relatively simple support due to mandatory single intake. Given this, to make intake a more beneficial process for Carers, intake staff or an online platform should be able to direct Carers to local community based services that can provide some level of service provision.
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<b>Education</b>	
<b>How can we encourage carers to access education support?</b>	We agree that Carers express that they are time poor and that they may be more inclined to access short-term services they report high satisfaction with such as respite rather than an education program that provides more longer-term benefits. We believe that 'education support' should be thought of more broadly. Through TACSI's Weavers program we have developed an evidence base of how this can be provided through peer support. Through connecting a Carer to someone who has been a Carer themselves, there is a wealth of knowledge sharing through personal experiences. This form of 'education support' is often more beneficial than a group or online education program. Knowledge, insight and problem solving borne out of lived experience of caring is extremely relevant and powerful and through this capacity building process builds long term benefits for the Carer.
<b>If education were to be offered online, how can we encourage carers to participate and complete an education programme?</b>	TACSI has minimal experience with delivering online education tools in relation to caring. Other services would be in the best position to respond to this question.

<b>Peer Support</b>	
<b>How can a peer support model be designed which encourage carers to participate and remain engaged?</b>	Through TACSI's peer-to-peer model 'Weavers' we have seen ongoing participation and engagement from Carers; either through ongoing connection and communication from their 'match' (their peer mentor who has caring experience) or from those who then become Weaver volunteers themselves once their caring journey has come to an end.
<b>What are some of the tools or supports which could assist in delivering peer support to a broader base of carers in a cost effective manner?</b>	Weavers is a low cost model with 1 FTE professional facilitator to 15 volunteers who can each support between 1 and 3 Carers at any time. There are a number of tools within this that make it low cost including utilising promotor networks as free guest speakers for the volunteers who can then distribute the information, as needed, to their peer match.

<p><b>Should peer support be a service able to be accessed without pre-conditions or structure processes?</b></p>	<p>We would like to challenge an underlying assumption that peer support, to operate effectively and at a low cost needs to be an unstructured process. The Weavers service as a structured peer to peer model is;</p> <ul style="list-style-type: none"> <li>- Based on theory and evidence: Ambiguous loss, narrative approach and adaptive caring.</li> <li>- It is individualised and works across the 4 key areas of need: navigating and negotiating services, sustaining things for yourself, connecting with family and friends, and emotional challenges.</li> <li>- It is flexible in that it can be face-to-face, phone or online or a combination of these over a specific time period.</li> </ul> <p>Peer support for Carers can be re-thought and re-designed. We have been demonstrating the model Weavers which brings into it key theories, mobilises people with past caring experience, it is timed and Carers don't have to meet a specific eligibility criteria. The value of peer support cannot be underestimated. Carers develop trust with someone who has a shared experience to their own and the level of support they are able to provide is unique.</p>
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<p><b>Needs identification and planning support</b></p>	
<p><b>To what extent do you think goal based planning should be used at the assessment stage of the process?</b>  <b>Given that a carer may not necessarily receive this, would a goal based planning approach be worthwhile?</b>  <b>To what extent should self-assessment form part of the future model?</b></p>	<p>We agree with the statement relating to the growing body of evidence that suggests early intervention may reduce the use of more costly and crisis services such as respite and residential care. The objective of needs identification and planning support to assist carers by identifying unmet needs and providing aid in planning informal and formal supports is positive.</p> <p>We believe that Carer self assessment should be part of the future model. Weavers uses a self assessment tool based on the 4 key areas of need (navigating and negotiating services, sustaining things for yourself, connecting with family and friends, and emotional challenges). Change happens for the Carer based on them being able to identify what would be most useful to them which includes the use of formal and informal supports.</p>

<p><b>Counselling</b></p>	
<p><b>What other counselling programmes and techniques would be beneficial in reducing carer burden?</b>  <b>Could these be delivered to a broader group of carers through telephone or online channels?</b></p>	<p>We challenge the assumption that counselling needs to be provided by someone with a formal qualification. Providing peer support, Weaver volunteers find themselves in incidental counselling roles. Through an induction and ongoing training process, volunteers are equipped to deal with this drawing on the 3A Grief Intervention model, narrative therapy, ambiguous loss theory and a strengths based approach. It is a</p>

	<p>combination of these and the fact that peers have a shared experience of caring that enable peer level counselling.</p> <p>Outside of peer level counselling, for support to be delivered through different mediums such as telephone and online is positive.</p>
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<b>A multi-component intervention</b>	
<p>Given that this model is seeking to apply preventative thinking, how can we ensure these supports are allocated to those carers who will benefit the most from them? What should be the criteria by which this is determined?</p>	<p>We are in support of the idea of multi component intervention - the key is about flexibility within these areas of finance, carer mentoring and respite, and individual and tailored family/carer need within these components. Drawing on the most important components of each intervention would allow people to access the supports they genuinely need which will be more effective.</p>

### Design progression questions and feedback

At TACSI, we have been involved in co-design methodologies and tools since 2009, the year that was established. The international team coming from Europe, USA, New Zealand and Australia, draw on their past experiences working in design consultancies and organisations.

Due to our years of experience in co-design, both in using and reflecting on the approach, process, methodologies and tools, we are delighted to read that a design approach has been taken and we are highly interested in knowing the detail of the followed process and the used methodologies.

We believe that the defined Design Progression is the adequate starting point. We will be very interested in the sharing of learnings on the process and approaches, in order to define the phases in detail. In understanding Carers perspectives phase for instance, during our research at TACSI in the discovery phase of developing Weavers; we saw the advantages of using ethnographic observations and spending longer time with people, rather than doing short time limited interviews. We have also designed and used tools in order to facilitate participants sharing their thoughts and ideas.

We are fascinated to read that you have co-created this draft service concept together with Carers, organisations who support Carers and the Carer Gateway Advisory Group. During our experience working with the ageing population we have encountered individuals, organisations and institutions developing inspiring projects around Australia and hope that there is further engagement as this progresses.

For further information please contact Kerry Jones, Lead Co-designer ageing and caring - [Kerry.jones@tacsi.org.au](mailto:Kerry.jones@tacsi.org.au)

## References

Australian Human Rights Commission, *Supporting Carers in the Workplace: A Toolkit*, 2013