



# **Sutherland Shire Carer Support Service Inc**

***'Caring for Carers'***

**ABN 67 860 764 301**

## **SUBMISSION FROM SUTHERLAND SHIRE CARER SUPPORT SERVICE INC. on the DRAFT SERVICE CONCEPT FOR THE DELIVERY OF INTERVENTIONS TO IMPROVE OUTCOMES FOR CARERS**

### **About Sutherland Shire Carer Support Service Inc.**

From 1996 Sutherland Shire Carer Support Service Inc. (SSCSS) has provided a wide range of support to carers in our community, through information, emotional support, referrals, advocacy, counselling, education and training, support groups and social activities. We are a not for profit, non-government, community-based organisation.

**Our Mission:** SSCSS aims to improve the quality of life of unpaid local carers. We do this by:

1. Supporting them in their role caring for a relative or friend who is frail or has a disability
2. Raising awareness about carers and their important role

**Our Vision:** A community where all carers participate and are valued

### **Our Values:**

- We are carer focussed
- We value diversity
- We understand local communities
- We are empathic and respectful
- We are flexible and responsive
- We are committed to what we do

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### **Introduction**

#### **P 4,5: Co-Design activities and the development of the draft concept**

- Sutherland Shire Carer Support Service Inc. (SSCSS) is the only stand-alone carer support service in NSW. SSCSS is a service provider of long standing which receives funding from the Commonwealth. We believe SSCSS can showcase a model of local carer support which is responsive and effective. Smaller organisations like ours have much to contribute to the development of the Carer Support Service Concept. We hope that smaller local carer support services like ours were included in the Subject Matter Expert (SME) Working Group and the environmental analysis (Current State Report).
- Our processes, staffing and priorities will differ from the larger CRCCs and Carers Associations, which are regional rather than local. We would welcome the Department of Social Services to visit our service to see how effective our local grass-roots model of carer support is. It is imperative that DSS has a comprehensive understanding of how existing local carer support services already operate on the ground, including CHSP services, Dementia Advisors and Younger Onset Dementia Key Workers.

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- The Service Concept Overview (p 21) indicates that all the proposed services to carers (except for financial support) will be delivered locally as well as nationally. Small carer support organisations are best placed to deliver services locally, close to where people live, making access easy, friendly, welcoming and efficient.
- Previous consultations proposed 4 models of integrated carer support, with respondents favouring the “hub and spoke” model to retain local supports.
- Page 4 of the draft Service Concept describes the Carer Gateway as a national contact centre. We are concerned that all carers will in future have to access carer support through this centralised contact centre, as with My Aged Care for older people. Our experiences with My Aged Care give us concern that carers might have to go through lengthy, unnecessary and frustrating screening and assessment before they can receive good support. Given that carers have been found to have very low levels of wellbeing and high levels of stress, it is desirable for them to still be able to contact local carer support services directly. Carers have told us that in some cases they have made the decision not to “bother” with services because they found the MAC contact centre too difficult.

#### **A. Statement of Need**

##### p 12: Current Carer Support Policy Framework

- On page 12 of the Draft Service Concept document, the two programmes “Dementia Education and Training for Carers” and “Counselling, Support, Information and Advocacy – carer support” should be listed separately.

##### p 14-19: Drivers for Change

- We support consistent provision of carer support services across the country. We maintain that unlike other modes of service provision to carers, our model of local carer support is not reactive or crisis-driven and offers opportunities for carers to receive peer, telephone and face to face support; socialisation, education and "time out" on a regular basis, all with a view to preventing burnout and maintaining wellbeing. These services can be provided in a very cost-effective manner, by developing partnerships with other local organisations and individuals, e.g. TAFE Outreach, local businesses. This model of local carer support could be rolled out nationally
- Page 15 states that “participants from the Carer Working Group reported that once they were connected with a carer support organisation they felt supported and had a sense of comfort knowing where to go for assistance.” Our repeated feedback from many carers supports this. We receive regular positive feedback on our face-to-face, telephone, group and on-line support and its benefits. Carers do not need to use these services continually, but to know they are available when times are tough is very reassuring.
- Carers' needs fluctuate and are not static. The many complexities of the caring role make it difficult to determine which carer is "more in need" than another. We do however agree that carers with multiple caring roles often have a need for more support.
- The caring journey can be of many years' duration, and carers need the option of accessing support at any stage of this journey so it is sustainable for them. This means they may have to refresh coping skills, information and education as their situation changes. That being said, there may be long periods of time when carers do not feel the need for support and therefore do not seek assistance or resources.
- Carers need to continue being supported during and after the transition into aged or residential care, as well as after the care recipient dies. These stages are the most stressful life events and many other services cease at this point, making carers vulnerable and isolated. Carers need continued access to emotional support and assistance with building a new life. At SSCSS we offer a Former Carer Support Group for bereaved carers. We also continue to include carers of people in residential care in our activities, as we, along with Carers NSW, still regards them as carers.

- We agree that the service system is hard to navigate (p. 16) and it is one of our major roles as a local carer support service to help carers identify and access the most appropriate supports, using our local knowledge and ongoing networking relationships. "Call centre" and "one stop shop" style services do not make it easier to navigate services, as they lack local knowledge and add layers of bureaucracy for carers to plough through. If centralised call centres must exist, they must minimise screening and direct calls straight to local service providers.

## **B. Draft Service Concept**

### p20, 21: Guiding Principles and Draft Concept

- p. 20: We agree with and support the Guiding Principles for the design of the new system, especially that carers are the core of its focus; that it is nationally consistent and locally responsive; that it retains the strengths of the current system, reuses existing infrastructure and is recognisable to both carers and local service networks. The design needs to recognise the many years of skill-building and staff expertise in carer support which already exists in the field, and utilise existing local services and networks which are already working well rather than dismantle them and start from scratch.

- Draft Service Concept (p21)

**Intake:** Great care needs to be taken in not making intake compulsory for every carer who makes contact, nor introducing intake too early. Carers first need a "soft landing" when contacting a support service, i.e. an empathic, listening response which lowers stress and anxiety and enables carers to later tolerate being asked personal questions during intake. This caring and empathic approach is essential for building trust and needs to be used for every carer contact throughout the carer journey. Many carers prefer to "try" a service, attending an advertised activity, before they would consider "signing up" for services.

**Peer Support:** The design concept seems to assume that peer support can/will happen through informal support networks or a local group. We know of some local examples of successful peer-led support groups and online support communities amongst parent carers. However, it needs to be stressed that the establishment and ongoing conduct of peer support groups requires networking, organisation and skilled facilitation. It should not be assumed that carers will be able to establish and sustain their own peer support groups over the long term.

As it states on page 30, strong feedback has been received that peer support should be included in a future support model, as an effective way of reducing social isolation. Concerns are raised that it would be too costly to implement professionally facilitated peer support groups nationally. Our experience at SSCSS is that carer support groups are very cost effective interventions with many benefits. Volunteer guest speakers and educational input can be planned by local carer support services. This ensures the sustainability and health of the support groups over time. Skills and planning do have to be put into groups in order for them to be healthy over the long term. Leadership training with an awareness of group dynamics is essential. The carer support group facilitation training available in NSW through Carers NSW and the Together Program recognise this reality.

We believe that carers should be able to access peer support groups without having to first undertake an intake process or meet pre-conditions. The facilitator would, however, need to ascertain if the carer meets the criteria for the group, by asking a simple question upon first contact.

### p. 26: Information Provision design considerations

- "While information is available through carer organisations today, as well as Carer Gateway, would individualised recommendations be of benefit when carers are undertaking or receiving other services? Individualised service provision is necessary for carers, not just with information provision, but in discussions of respite needs/options, groups, home support services, coping skills and counselling interventions.

Skilled carer support workers at the local organisation level can do this, and already do this, by giving information and options at the appropriate time and in the appropriate format, addressing carer guilt, grief and other emotions, and assisting carers to navigate the service system to overcome the paralysis that can come with information overload. This model has been developed over 20 years, with 360-degree evaluation and continuous improvement processes.

p. 32: Needs identification and planning

- Self-assessment is a very good idea, either individually or jointly with a support worker. It is consistent with consumer directed service principles and hopefully less lengthy and invasive than other assessment tools.

p. 33: Multicomponent intervention

- A combination of interventions woven into one is a good concept for minimising the number of providers involved, and increasing the effectiveness of each by combining them, e.g. respite use made more likely and more effective through mentoring on guilt/separation, assistance with planning, and funding. There are many barriers for carers to respite use, and this approach would help to overcome these and Facilitate the earlier use of respite.

Multicomponent interventions should be available to all carers in any situation, including those caring for someone who does not qualify for a funding package or program. This should include carers who do not qualify for Carer Allowance. These carers may be in particular need of support at certain life stages, since the care recipient might not be accessing much support themselves.

The provision of funding packages raises many potential difficulties. This model may not work for carers. Firstly, it would be very complex and inequitable for some carers to receive funding packages and others not. Secondly, the relatively small amounts of funding for each package may make it unworkable to administer them. Thirdly, a lot of carers, particularly older carers, would feel overwhelmed at managing a funding package for themselves, as well as potentially a package for the care recipient. In conjunction with continuing block funded local carer support services, a universal voucher system could be a viable alternative, with carers being issued vouchers for education, respite, support groups, counselling and mentoring. Targeted vouchers send the message that the carer has needs in their own right which should have equal priority with the care recipient's needs. For respite, an annual bonus payment through Centrelink may be more efficient than a funding package. Carers would have the option of paying friends or family members to provide respite, which is often a preferred option for both carers and care recipients.

p.45: Supporting All Carers – CALD Carers

- We agree that “there is a need to ensure services are accessible in order to raise awareness, provide information and conduct needs identification at a local level where carers...are not able to, or are uncomfortable accessing national infrastructure to seek support.” Our CALD carer support groups for carer from Chinese, Greek and Spanish language backgrounds provide bilingual facilitation and allow local access to support and services which is culturally and linguistically appropriate and comprehensible.

P 47: Providing Integrated Support: Support to Access Employment

- Carers needing to return to work after their caring role has ended often experience financial and emotional stress, as well as physical illness or disability as a result of the demands of their caring role over many years. These factors should be addressed in support to access employment. These former carers may also need mentoring, counselling and other supports to aid their recovery before they can realistically obtain employment.
- The Integrated Carer Support Service can utilise tools which have already been created to assist carers access employment. For example, the NSW Dept. of FACS has recently created the SkillsLink2Work website/App to assist carers identify the skills they have developed through their caring role and to translate those skills into the realm of paid employment.

P 59, 60: What Interventions are supported by evidence?

- p 59: States that of the 3 categories of intervention supported by evidence, both Category 2 (Psychotherapy – Counselling) and Category 3 (Multicomponent studies) are “said to deliver the most effective interventions.” This needs to be clarified?
- p 60: States that education, training and information increases carer knowledge, abilities and possibly also mental health and coping, particularly when active and targeted rather than passive and generic. This confirms our experiences as a local carer support provider. Education, training and information provision must be targeted to local needs rather than only provided on a national website. This targeting can only be done by local services which can research and consult locally, then tailor programs accordingly.

General Comments

- Some terms may have to be de-stigmatised and normalised for carers. For example, counselling and mentoring may be interpreted by some as implying that the carer is failing. These interventions need to be communicated in terms of maintaining carer wellbeing under challenging and stressful circumstances.
- State Governments and Carer Associations have already done a great deal of research, needs analysis and development of resources relating to carers. It would be very important for the Commonwealth to seek out and utilise this as part of the Integrated Carer Support Service. For example, existing state-based Apps, websites, factsheets, publications and forums can be tapped into.
- **ALL carers need to feel comfortable in accessing support. Services to carers therefore need to have an ethos of being user-friendly, non-invasive, responsive, flexible and empathic. Services to carers, from initial intake through to direct service provision, need to be delivered by staff who are trained, skilled and experienced in carer issues. Many carers are unwilling and hesitant about seeking support; all interventions must build rapport and trust.**
- We strongly argue for the maintenance of smaller, local carer support services as an essential component of an Integrated Carer Support Plan, because they have proven to be responsive, flexible, connected with local networks and skilled in providing effective and cost-efficient support to carers over many years. These services have a preventative focus, reduce carer isolation and foster carer wellbeing by building community links. We recommend the duplication of this model of local carer support across the country, as a vital component of a “hub and spoke” design.

**Report compiled by Leonie Puckeridge, Carer Support Co-ordinator,  
Sutherland Shire Carer Support Service 25/5/16**