Department of Social Services
Tuggeranong, Canberra ACT

ANGLICARE SA

Response to a call for written submissions

Designing the new integrated carer support service

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Response to call for submissions by the Department of Social Services

Organisational background

AnglicareSA has been working for the community of South Australia for over 150 years. Our 1700 staff and 700 volunteers support nearly 55,000 people each year. AnglicareSA's diverse community services include aged care, disability, foster care, parenting, financial literacy, new-arrivals, Aboriginal services, emergency assistance, homelessness and mental health.

Overall comments

AnglicareSA welcomes the Government's commitment to the design of a new integrated carer support service, and we commend the invaluable contribution of Australia's 2.7 million carers to the health and wellbeing of the individuals, families and communities they support.

AnglicareSA is committed to transparent, respectful and consumer-led inclusion of carers and consumer support networks across all our services. In particular, AnglicareSA provides residential aged care, independent living, community based care and home supports to over 4,600 consumers and their carers annually. We support approximately 400 foster carers every year, and more than 850 children and adults with physical and/or intellectual disabilities. Many of our community services continue to evolve through co-design and collaboration with consumers and their primary carer/s.

AnglicareSA's DSS Integrated carer support system response has been informed by services which engage extensively with carers. It also draws on a service evaluation and carer focus group conducted by our Mental Health Respite (MHR) service which supports approximately 400 carers and their families annually.

AnglicareSA supports the objective of the future model to assist as many carers as possible, however, in view of their fundamental importance to both a healthy society and viable future health system, suggests more funding be made available to reinforce and strengthen carer supports into the future.

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
Awareness	If the proposed model for the integrated carer support system is to achieve a preventative focus, it will be important to identify carers early in their caring journey and connect them to potential supports. For many carers, this occurs within a healthcare setting, where the person they are looking after may be diagnosed with a condition. The challenge in doing so is that carers are commonly focussed on the needs of the care recipient, rather than how they will manage their new role.[1] This sentiment was reiterated by the Carer Working Group where carers in the group expressed that brochures were simply put in a drawer and not reviewed unless it was of benefit to them at the time. Given this, what would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?	24	Carers tend to have minimal knowledge and awareness of available supports, and only seek this information when a crisis or other need arises. Raising awareness through a primary health model could optimise individual knowledge and build social capital. Partnerships with medical and specialist services are essential for connecting with and supporting carers early. For example, health practitioners could facilitate an introduction to carer support services at their next appointment. Alternatively, a peer visiting service could see the family/carer receive a visit from others who have had similar experiences, providing face to face contact and support. Ideally, this role would be from someone who understands the available services and supports in the carer's community. Experience from our MHR service shows that people are unlikely to identify as carers in the early stages of diagnosis, particularly if they are in familial roles. The term 'carer' can carry its own stigma, and early stages of the caring role can include loss and grief issues and intense focus on coping strategies and future planning. To raise awareness for individual carers early in their caring journey, a marketing strategy using a variety of mediums – internet, fridge magnets, wallet cards, event sponsorships, and possibly using different terminology to engage carers,

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[1] For example, a study involving the delivery of carer focussed information in a written format within a healthcare setting led to carers overlooking important information which may be of benefit to them (Grande, Austin, Ewing, O'Leary, & Roberts, 2015).

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
			should be considered, preferably with carer focus groups. AnglicareSA's 2014 MHR Carer survey found that 65% of carers discovered services through word of mouth or organisations they are currently involved with; the remaining 35% obtained information from the internet, newspaper, television or other sources. 'Bring a friend' days are encouraged at carer events, in order to build awareness and provide security for new carers and their support networks to actively share experiences, strengthen their supports and introduce others through word of mouth.
Awareness	A key group of carers for whom awareness will need to be targeted is young carers. Young carers include unpaid carers who range from young children to teenagers (4-17 years) and young adults aged 18 to 24. Purcal and Co (2012) argue that the most desirable service goal for young carers is prevention. A primary facet of this involves identification of young carers as early as possible by health/disability services, particularly if formal services may not be adequate to negate the need for a caring responsibility to arise or become entrenched. In considering support for young carers, to what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner? Purcal and Co (2012) suggest that a more holistic approach to whole of family support should be taken from the outset within the health care setting. While	24	Raising awareness of young carers needs a multidimensional approach. Marketing and promotional material should be youth friendly, easy to read and produced in non-clinical and non-service language, using bright colours and messaging that young people connect with. Young carers want to know how they will benefit by contacting the service and need to understand supports available by the utilisation of plain language and visual cues. To facilitate access to supports for young people, public transport, safe environments and collaboration with youth services are critical. Further, schools and universities are important – building capacity of teachers and school counsellors to identify and refer young carers, together with health services. Fear-based responses are also common in

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
	schools are a potential point of identification, they may only identify young carers once they have become entrenched, such as where absences are observed or academic performance lowers. If this is the case, should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than in schools?		young people, so providing safe and supportive environments for them to ask for help is very important. For young people, a point of difference often equates to a 'reason to bully' for them, so efforts to consider reframing the term 'carer' may help to reduce the stigma associated. Safe, supported environments also increase the likelihood of young carers asking for help, and increasing awareness. In addition, reframing the carer-caree connection as a productive and positive dual relationship is important in helping to reduce the stigma associated with the caring role. There could also be scope to incorporate awareness of young carers into mainstream curriculum. This could be adapted into a broader, integrated early intervention approach for identifying young carers as well as young people at risk of and/or experiencing homelessness, domestic family violence etc. A youth phone in service, via Kids Help Line (4-12 year olds), Life Line or similar service may offer a soft, alternative medium for young people to access services in an anonymous and non-confrontational way. Providers could also work with hospitals and health services to develop and market carer programs which are fun, connect carers to supports and facilitate productive carer-caree relationships.
Information provision	Feedback from co-design participants to date has indicated that information provision must be tailored to a carer's	26	Yes, however, individualised recommendations should be viewed in the context of a continuum of support options

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
	individual situation or it is of limited value. 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?		available for carers, from low to high needs, bearing in mind this is often and continually changing. This acknowledges that carer needs fluctuate, and fluid/responsive solutions that acknowledge and respond to their current need provides a more holistic and realistic spectrum of support. AnglicareSA's MHR service receives the majority of referrals when the carer or caree is in a crisis situation, and interventions may span other domains including financial assistance, homelessness, clinical and/or correctional services. An individualised approach is necessary, however, to achieve the best longer term stability, the carer and caree should understand that supports are available to them when their crisis subsides. Prevention of recurrent crisis depends often on the knowledge of ongoing supports available.
Intake	Intake is intended solely to be a service which facilitates access to certain supports. As it involves the collection of information, it does not generally offer carers an immediate benefit in exchange for the provision of this information. Given this, are there ways to make intake a more beneficial process for carers? For example, carers and organisations assisting carers today have indicated how important having plans in place is to carers, that it provides a sense of certainty and relief. In undertaking intake (either through phone or self-service online) carers could opt to register their emergency plans with the service so that in the event of an emergency, information can be readily accessed to deliver respite support.	27	Self-assessment via the internet which generates self-referrals to services and supports available in the community is an excellent option for carers with computer access. Feedback from some older carers is that they do not have access to, nor are comfortable with the use of computers and would prefer face to face contact with an experienced professional. Diverse support responses should be available, such as; someone will call you, opt to receive information via post, online forum options, someone will visit your home to discuss etc.

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
			Providing the option to register an emergency plan is also a good engagement and risk mitigation approach, however, supports (other than online templates) should be available to help carers develop and maintain these. Carers build relationships with stakeholders who provide services, tailored to their individual need. Emergency plans should be maintained with the service provider, rather than the broader intake service to ensure that updates are completed and risk to attending persons minimised. Carers often require ongoing services to enable them to plan and develop sustainable strategies, rather than one off service provision and support. An anonymous referral option will encourage an inclusive and participatory approach that meets carers where they are at and the level of engagement they can commit to at that point in time. Safeguards are, however, essential when face to face support is provided, at which point carers will need to provide a prerequisite (minimal) level of information.
Intake	Another way to ensure that intake is of direct benefit to carers is to limit its utilisation to those times it is necessary. Given this, when should intake be a mandatory process? For example, to what extent would intake be required to facilitate access to peer support or education? While it will be important as part of the future service to measure outcomes of the interventions developed so as to build upon	27	Assessment/intake is necessary when there is face to face contact with staff. Formal and informal assessment processes could be developed and tailored to the different level of need and supports being accessed by carers at that point in time, with an emphasis on streamlined and minimal administration. This process also assists services to ensure they are able to continually develop and address the current

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
	and improve their delivery, this additional administrative burden may represent a barrier to people otherwise accessing these services.		needs of the community.
Education	As stated earlier, research suggests that carers may be more inclined to access services they report high satisfaction with such as respite. However, education programmes commonly provide longer term benefits to carers. Carers report they are commonly time poor and dedicating time to undertaking an education programme may not be perceived as helpful by carers. Given this, how can we encourage carers to access education support?	29	By listening to carers, we can adapt services that meet their needs, including targeted education. For example, by listening to the carers we support, AnglicareSA adapted our MHR service to provide more tailored and direct carer support (in addition to respite). Carers told us 'I'm tied to my house', 'I don't have any friends', and 'I want someone to listen to me, not just the person I'm caring for'. We subsequently adapted from being a sole respite provider, to delivering 50% carer services and 50% respite/caree services. We now offer regular carer events, such as High Teas and dinners (which are often booked out within 24 hours of distributing invitations), as well as carer and caree social skills and group programs. These programs aim to reduce social isolation and provide means to connect, develop friendships and extend their support network/s. Education should link with dual respite and social activities. Social events with a subliminal education focus including guest speakers are very effective, as is education through fun. Less clinical marketing and service terminology should be used to build understanding, and foster confidence and trust. Carers often report overload as being a cause for reaching crisis point as a result of fulltime caring. Lack of engagement in services results in carees requiring in-home fulltime care, social isolation and an inability for carers to access personal

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
			pursuits or wellbeing activities. Carers view the carees welfare as their primary concern and more often than not, will not pursue their own interests if carees needs are not met first (respite).
Education	While online education is a cost effective and efficient way to deliver education programmes, research suggests that achieving high completion rates can be challenging. If education were to be offered online, how can we encourage carers to participate and complete an education programme?	29	From our experience, carers often want to have someone to talk to and feel understood. They sometimes lack motivation to pursue their own interests and have little self confidence due to social isolation. Carer social programs have been fast growing and beneficial in improving carer wellbeing, especially when a parallel program is facilitated at the same time for the caree (as per AnglicareSA's MHR service). Online education may be counterproductive to the needs of carers, as it may be viewed as being further isolating and generic without supporting carers to feel valued or connected, particularly as many carers are often older persons with no access to computers or willingness to learn to use them. Online education should be considered as one aspect of available resources.
Education	There are many organisations which run education programmes for carers funded through programmes outside of the Department's carer support funding and will continue to do so in a future model. Given this, how can the future Integrated Carer Support Service help carers to be aware of, and access education which may be relevant to them outside of these carer focussed supports?	29	Central information hubs, active promotion to GPs, mainstream health services and hospitals, information days and events and targeted sponsorships can help build awareness of education services and supports. Services should always involve carers through co design concepts and develop programs that reflect outcomes of this consultative process including communication and promotion. Carers strongly identify respite avenues as the

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
			only opportunity for them to explore other activities. AnglicareSA's MHR carer-focus group in May 2016 identified their preferred methods for communication were: email, text message, peer-run Facebook, newsletters (post and electronic), brochures via the post and internet. Additional supports they would like to access included: - **Education:** "I am caring" courses, more behaviour-specific training, skills training for caring roles, work skills to maintain employability whilst caring, personal wellbeing courses. - **Social activities:** Carer days such as Art Groups and writing groups - **Peer groups, including** young carer or behaviour specific groups, group events to address isolation. - **One-on-one supports:** including transition assistance to independence, Emergency Financial Assistance, counselling, support to navigate the system, and clinical support during admission. Many of these findings can be generalised to carers caring for people with physical disabilities or for the aged.
Peer Support	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? Currently, some models of peer support involve use of professional facilitators or guest speakers. Implementing these	30	AnglicareSA's experience is that peer support groups are an effective means for connecting a broad base of carers. Carers are often happy to offer time to services they enjoy participating in and feel valued by, and are enthusiastic to contribute ideas for guest speakers and workshops.

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
	models nationally may be too high in cost to sustain in the longer term. Given this, how can a peer support model be designed which encourage carers to participate and remain engaged? *e.g. The Council on The Ageing (COTA)'s volunteer peer educators is one avenue which delivers peer support to a broad base of carers in a cost effective manner. https://www.cotasa.org.au/Programs/Resource/default.aspx*		Facilitators are, however, viewed as critical enablers to coordinate and drive their success as the administrative burden of sustaining peer support groups can be overwhelming. Alternatively, small or in-kind payments or collaborative approaches could be explored. Peer support workers require a similar duty of care as an employee by an organisation, to ensure the appropriate training, mandatory clearances, accessibility and physical and psychological welfare of participants, which comes at additional and ongoing costs.
Peer Support	The evidence suggests that peer support groups, when used as a standalone intervention, may not be particularly effective. However, peer support may provide a way for carers to connect with the Integrated Carer Support Service in a less formal way. For example, a carer may first join an online forum before deciding whether to proceed to seek more help. Peer support, when used in this way, may help encourage people to engage more using channels such as social media. Consultations to date have highlighted this may be beneficial in reaching those carers who may not have otherwise have sought formal support such as young carers and Aboriginal and/or Torres Strait Islander carers. Should peer support be a service able to be accessed without pre-conditions or structured processes?	30	Profiling stories of successful peer supports encourage participation, provides a safe opportunity for potential participants to engage, and generate interest around contributing based on personal experience. A minimal level of information (as opposed to set 'pre-conditions') should be required from participants interested in peer support services, ensuring adequate duty of care to those involved. Further, AnglicareSA has observed some peer support groups fragment and dissolve when coordination support is withdrawn, resulting in the activity becoming counter-productive to the program's intent. Structured processes can mitigate this risk, and increase the longevity and sustainability of peer support networks. The option for carers or carees to withdraw (without

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
			judgement) in times of crisis, personal reasons or high stress are important in providing a safe and supportive environment to participate. Respite options are also essential incentives to encourage and support carers to join in and participate in peer support groups. Pre-planning activities through co design concepts, further support people to participate in the development and engagement of peer support groups. A clear and accessible complaints and feedback process is also essential to embedding a commitment and culture of ‘being heard’, ‘listening’ and respecting carer needs as they continue to fluctuate, especially in the mental health areas. AnglicareSA’s MHR carer-focus group (May 2016) identified the following benefits of peer support and dedicated carer support activities like those provided by MHR: “they help me feel normal again”, “I feel recharged and ready for the next day”, “I couldn’t live without it”, “I need to know there is a real world out there”, “helps me build up the strength to face it all again”, “provides time to think about me”, “I go from being worthless, to being somebody”. Suggestions to improve activities and facilitate greater participation were to provide an annual calendar of activities, information evenings/days about what is happening in the coming months, and increased collaboration with other service providers.

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
Needs Identification and Planning	To what extent do you think goal based planning should be used at the assessment stage of the process? Goal based assessment and planning approaches are common to Consumer Directed Care principles, usually in conjunction with a funded package or financial allocation of some form. Given that a carer may not necessarily receive this, would a goal based planning approach be worthwhile?	32	Goal based planning supports purposeful and meaningful engagement between a Carer, caree and their support networks. It provides a clear collaborative pathway which identifies carer and service responsibilities for support outcomes. Flexibility to modify goals to reflect changing situations ensures a practical framework for engagement. It can also reduce the risk of carer's misappropriating funds, and the possibility of carer's sabotaging situations to foster unhealthy caree dependencies.
Needs Identification and Planning	To what extent should self-assessment form part of the future model?	32	An option for self-assessment is important, as it provides an avenue for autonomous self-assessment and automated generation of self-referrals to community and other relevant local support services.
A multicomponent intervention	Multi-component support seeks to amplify the effects of the supports by combining them. While all carers could benefit from these supports, funding will not extend to providing this type of support to all carers. 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?	34	Intensive and complex responses should be developed to meet the need of each individual. They should be provided in a 'stepped-through' approach, emphasising short to medium term support options tailored to the breadth and depth of each individual's need/s. In this context, short term interventions should have longer term linkages, with the view to reducing over time.
Multi-component Support 1: Financial	Where funding allocated to individuals as part of a financial support package is not high (c.f. some disability packages being in the tens of thousands), the overhead and administrative cost may not be worthwhile to put in place	37	AnglicareSA agrees with empowering carers to self-manage individual packages. Carers should have a choice to their extent of their input and

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Support	accountability measures for individuals to demonstrate how funds were spent. While some carers have indicated they would be happy to manage a package, others in older demographics have indicated this would be yet another burden. Some carers have openly indicated that if there were no controls applied to these funds, they would have spent the funding on the person they cared for, rather than on supports to help them as a carer. How can we help carers to use these funds appropriately without large administrative burdens on carers or providers who may be assisting them?		control of financial management. Co design philosophies will optimise engagement and service planning and at times this will inadvertently require administrative burden. Allocating funds within broad classifications such as 'respite' or 'community participation' may provide parameters to spend it as intended. We believe existing assessment and acquittal processes should provide adequate accountability; we don't think arduous administrative controls are warranted to monitor spending. Maintaining funding for carer events, wellbeing courses and large social opportunities ensures accessibility for new carers and others such as young carers, without individual funding. Pre-planning, promotion and organisation of events is imperative to reaching carers, carees and families.
Multi-component Support 2: Carer Mentoring	It is evident from our research and from consultation with carers and organisations that carers' needs vary over time. This integrated carer support system is intended to provide carers with goal based planning and coaching support. Coaching programmes are normally funded for a time-limited period such as the Stronger Carers Programme 10 week programme or beyondblue's New Access Coaching Service. When would a coaching programme be most effective for a carer?	39	Activating supports alongside a continuum of need is most effective when organised in an ongoing consultative process with both carer and caree. Coaches can be effective in identifying strengths, goals and also coping strategies. They may be most effective during times of transition, such as early diagnosis to build confidence, support for routines, or when adapting to significant change such as when a caree has left home.
Multi-component	Some carers may not want a coaching programme which extends over time, despite the potential benefits, preferring	39	No, coaching should not be mandated. This would contradict the overall principles of the reform, and what AnglicareSA

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
Support 2: Carer Mentoring	only intermittent contact when they feel they need it. Given this is intended to be part of a multi-component support model, should this be a mandatory part of the service? Or should mentors should be able to determine whether the carer has the capacity to forgo coaching until another time?		services observe as being beneficial. Carers like to feel in control of their situation, understood, valued and provided with opportunities to meet and learn from others in similar situations. From our experience delivering programs that support carer wellbeing, it has been observed that carers will disengage with services or educational opportunities very quickly, if they feel their caring role is undervalued. Carers may view the concept of 'coaches or mentors' as intrusive or a 'big brother' approach. A strengths-based approach which is carer driven and determined is essential to laying a strong foundation for more effective future carer supports.
Multi-component Support 3: Respite support service	The inclusion of respite support within a multi-component support package is consistent with recommendations arising from the literature. A number of carer organisations have reported anecdotally that more flexible responses, such as brokered respite, have resulted in longer term outcomes. It is for this reason that this service is proposed to be coupled with financial support, as a form of consumer directed respite and coaching. This could mean a shift towards using respite as a complementary, not primary support. Will moving to more of a consumer directed model, where funding is attributed to an individual carer result in unintended effects? What might these be and how can they be mitigated?	41	Consumer directed respite enhances carer choice and ability to navigate the supports they need. Consumer directed funding could work by linking funds to specific support areas such as respite, community engagement etc, with the carer required to spend the funds in these domains. Funding for this type of service should take into consideration respite options, which will vary depending on carer and caree needs. For example, a carer may need a break and seek respite for the week-end. This may be either in home or at a respite facility, if the carees needs are complex. A carer may wish to attend a carer event to reduce social isolation, where respite would be required for this period of time at the home or in the community. A carer may wish to attend a 6 week course, respite would be sought for a regular time each week. Respite funding needs to consider that more often than not,

Theme	Design considerations from consultation paper	Service Concept Page #	AnglicareSA comments
			respite is taken outside of traditional working hours. It would be difficult for carers to know in advance their respite needs as short courses, events and programs are generally promoted around 3 months in advance. Mental Health carers are faced with additional complexities regarding episodic crisis, which are unpredictable and may span days to months. In the absence of funds, carers may experience extensive behavioural problems, domestic violence or other traumatic situations.
Counselling	While counselling has been shown to be highly effective at reducing carer strain, delivery of counselling to large numbers of carers is challenging due to the resources involved. Similar challenges are being faced in the mental health sector where many people who would benefit from counselling are unable to access the service due to long waiting lists and high costs. Comparative research of delivery modalities (i.e. telephone counselling versus online programmes) has demonstrated that digital and telephone counselling are as effective as face to face counselling. Utilisation of lower cost channels such as telephone or online to deliver counselling will mean more carers will be able to receive counselling. Are there any concerns with using lower cost channels?	43	Counselling should be available to all carers, carees and immediate family members. This is an evidenced model of support that assists with prevention through to highly complex and traumatic situations. An easily accessible range of options is important to enable choice, flexibility and affordability, however, online/telephone counselling should not be offered as an alternative to, but as an additional access point. Lower cost channels can diminish service effectiveness, however, telephone/online options are definitely appropriate as an after-hours support option.
Counselling	Much of the evidence relating to effective counselling programmes for carers is focussed on CBT. What other counselling programmes and techniques would be beneficial	43	Strengths based counselling programs which explore and foster emotional intelligence. These may be adapted to online and telephone options, particularly as an after 5pm

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	in reducing carer burden? Could these be delivered to a broader group of carers through telephone or online channels?		service solution. Recognition of the importance of individual spiritual and value based beliefs are also important across a variety of religions and other models of support such as meditation, reiki etc, delivered within a person-centred, holistic and strengths based approach.

AnglicareSA asked our MHR carer-focus group (May 2016) what impact reduced carer services and supports would have on them and their role as a carer; some of their responses included:

- ‘It would impact my own health’
- ‘I would have no support and be house bound’
- ‘there would be higher suicide rates’
- ‘I would not have any transport’
- ‘nowhere to meet people or engage in community’
- ‘more begging’
- ‘I am getting old and tired. I have been a carer all my life, in one way or another and live in poverty because of it’

‘Designing the new integrated carer support service’ provides a unique opportunity to raise the profile of carers, and equip them with the recognition, resources, confidence and ability to sustain their caring role; this role strengthens our homes and families, our communities and our broader health and social services system. AnglicareSA commends the efforts going in to this reform, and welcome further consultation and participation in its ongoing development and implementation.