

Department of Social Services
Tuggeranong, Canberra ACT



Response to a call for written submissions

Delivering an integrated carer support service:

A draft model for the delivery of carer support services

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Organisational background

AnglicareSA has been working for the community of South Australia for over 156 years. Our 1,800 staff and 700 volunteers support approximately 58,000 people each year across disability, foster care, aged care, youth, parenting, financial literacy, new-arrivals, Aboriginal, emergency assistance, homelessness and mental health services. AnglicareSA provides community based care, home supports, residential aged care and independent living to over 4,600 consumers and their carers annually. We support approximately 400 foster carers, more than 850 children and adults with physical and/or intellectual disabilities and their carers, and provide counselling and crisis intervention supports to over 200 carers of people with mental illness. Many of our community services continue to evolve through co-design and collaboration with consumers and their primary carer/s.

AnglicareSA's vision is for "Justice, Respect and Fullness of Life for All". We are here for every South Australian in need, with an emphasis on 'Connecting People to Place' through our Strategic Priority Area of Strengthening families and communities: providing individuals, families and communities with the tools to succeed.

At AnglicareSA we are guided by the following five values:

- Integrity
- Compassion
- Stewardship
- Equity
- Servant Leadership

Each of these values are integral to the work we do across our organisation. They are what drive us each day in working to make a difference in the lives of South Australians.

Overall Comments and Recommendations

AnglicareSA's response to the draft model for the delivery of the Integrated Carer Support Service (ICSS) builds on our June 2016 submission regarding the design phase of the service. AnglicareSA believes the objectives of the proposed ICSS (pg7) and mechanisms identified to achieve them are clear, carer-oriented and focused on streamlining access to and maximising supports for carers.

AnglicareSA is supportive of the ICSS' general framework and proposed structure and principles, however, our primary concerns focus on embedding and amplifying carer voice and need, including types of services funded, how services and systems interface to respond to and support carers, how Regional Hubs remain committed to and aware of what is happening in the carer community and responsive to local need; and, how choice and control is enhanced and not compromised by ensuring services are viable and effective across a continuum of need (immediate, short-term and ongoing) to help carers sustain their caring role.

Key Recommendations

- **Recommendation 1. Funding for respite:** for the ICSS to provide adequate and flexible funding for carer respite, particularly for those who have been unable to secure respite through NDIS or the aged care system, and for emergency and crisis situations.
- **Recommendation 2. Collaboration to achieve sustainable respite options:** for the ICSS to work in collaboration with NDIS, the Department of Health's Ageing and Aged Care division, non-government services, community networks and care recipients to analyse availability, uptake and quality of respite options for carers, and co-fund pilots with respite providers to develop best practice models that are sustainable and responsive to care recipient needs. Carer wellbeing needs to be recognised as essential to the future sustainability and success of the NDIS and Aged Care reforms.
- **Recommendation 3. Community based respite options:** to increase the availability of flexible, community based respite options, particularly for carers in crisis, carers with limited support networks, older carers and those carers who are social isolated. AnglicareSA's dual community based Mental Health Respite service for carers and care recipients through group activities for care recipients, whilst providing opportunities for carers to attend to their own personal wellbeing and life goals, through social, educational, recreational and employment related opportunities.
- **Recommendation 4. Restorative residential respite models:** to advocate for a review of the Aged Care residential respite system with a focus on restorative respite models.
- **Recommendation 5. Planned respite:** to increase opportunities for planned respite within a residential facility with secure tenure, providing assurance and certainty for carers and care recipients; this is critical to carer wellbeing and sustainability.
- **Recommendation 6. Carer wellbeing supports:** to include psychosocial carer supports which build on the social, emotional and community networks around carers and strengthen their informal networks.
- **Recommendation 7. Streamlined supports:** to reduce the number of contact points and time carers spend navigating supports by triaging calls and linking them to local services and face to face support as soon as possible. Local knowledge is important to optimally connect carers to local networks and resources.
- **Recommendation 8. Collaborative Governance Arrangements:** for Regional Hubs to pursue joint governance arrangements with local community and service providers, ensuring strategic and operational alignment and a common understanding of priorities, resource allocation processes, and local need (The Tasmanian Disability Gateway's 2013 Evaluation demonstrates the effectiveness of a shared governance approach: http://www.dhhs.tas.gov.au/disability/projects/mid-term_review_of_disability_gateways).
- **Recommendation 9. Broker block funded and fee for service programs:** to broker a mix of block funded and fee for service programs at the local level, informed by joint governance and decision making processes which includes carers and local carer support services.
- **Recommendation 10. Evidence based services:** to create an evidence base of carer services which are currently delivered, have been co-designed with carers and provide an insight into 'what works', thereby, capturing the investment in carer supports to date.

1. In relation to the program overview, do you believe that the objectives, outcomes and delivery principles are appropriate for the services required to be delivered under each program?

AnglicareSA believes the objectives and outcomes for the services required to be delivered under each program are appropriate, however, we have concerns regarding *8.2c Planned Respite: Assistance to access planned respite (funded through other services)*.

Respite is consistently identified as one of the most valued support options for carers, enabling them to 'keep going' and maintain their own wellbeing. The ICSS, NDIS and aged care reforms do not adequately acknowledge this, or the benefits which respite offers carers and their ability to sustain their caring role. 8.2c raises concerns that planned respite will only be available through NDIS and aged care systems, which creates limitations and challenges regarding the long-term availability and sustainability of planned respite for carers, specifically:

NDIS: In AnglicareSA's experience delivering planned respite through NDIS, we have observed the following issues:

- **Reluctance to fund respite:** Respite is stigmatised within NDIS and some planners have the view that respite does not contribute directly to the wellbeing of the participant. This concept devalues carers, and is an unhelpful division that undermines the very strong evidence that participant wellbeing is clearly linked to the wellbeing of their primary carer/s.
- **Funding:** currently, there is no financial loading for respite on week-ends, impacting the availability and viability of quality respite options. As providers are unable to sustain the cost of operating week-end respite over the longer term, available respite options may reduce thereby, compounding stress on carers and participants.

This challenge, and the implication on the sector was echoed by Dr Ken Baker, CEO National Disability Services recently:

"The consolidation of a single price across the week, regardless of weekend or evening, penalty rates, the short-term accommodation, what used to be called respite services, is meaning that financially you cannot provide the services at the times of the week when people want them.

That has become a significant risk to respite services. Because those short-term accommodation houses do not attract specialist disability accommodation providers, which some do, some providers are saying that I cannot afford to run it as respite, so I will convert it to long-term accommodation. That is not a good outcome for the families and the people with disabilities who need respite, centre based respite.

Our 2016 State of the Disability Sector report also showed that of the organisations surveyed 13% providing respite services plan to either reduce or stop providing these services in the next year."

- **Terminology:** respite is called ‘short term accommodation and assistance’ in NDIS, creating confusion when carers are trying to support participants to negotiate their plan, and often find themselves compromised in advocating for their own needs and the needs of the participant.

Aged care: From a carer’s perspective, there are systemic flaws in the Residential Respite approach within the aged care system, including:

- **Limited forward planning and access to residential respite:** Many aged care providers’ preference to not dedicate identified respite beds due to financial structures and incentives leads to limited access to and availability of planned residential respite options.
- **Security of tenure:** Providers’ ability to withdraw placements at short notice if the care recipient is deemed unsuitable (i.e. providers can cherry pick care recipients), means carers are left in the position of either hospitalising the care recipient, or the situation escalating into a domestic crisis situation.
- **Limited access to wrap around services eg. Allied Health:** Inability to access wrap around services such as Allied Health during residential respite, means the health of the care recipient often deteriorates during their respite stay.
- **Need for a Restorative Approach:** aged care respite providers do not embrace a restorative and wellness approach; anecdotally, carers report deterioration in status during residential respite stays.
- **Access issues:** There is evidence that some My Aged Care processes are separating carers and carer recipients e.g. in the registrations and assessments process, rather than treating them collectively in response to respite related needs, and that respite is not being prioritised by My Aged Care.

Respite plays an important role in enabling older members of the community, especially those who are frail, with dementia or challenging behaviours, to remain living in their own home. Periodic episodes of respite reduce the prospect of early entry to residential care. Respite can also provide a safe and time limited introduction to out of home care, with increased exposure over time building a bridge to residential care where permanent care may be an eventual necessity.

Recommendation 1. Funding for respite: for the ICSS to provide adequate and flexible funding for carer respite, particularly for those who have been unable to secure respite through NDIS or the aged care system, and for emergency and crisis situations.

Recommendation 2. Collaboration to achieve sustainable respite options: for the ICSS to work in collaboration with NDIS, the Department of Health’s Ageing and Aged Care division, non-government services, community networks and care recipients to analyse availability, uptake and quality of respite options for carers, and co-fund pilots with respite providers to develop best practice models that are sustainable and responsive to care recipient needs.

Recommendation 3. Community based respite options: to increase the availability of flexible, community based respite options, particularly for carers in crisis, carers with limited support networks, older carers and those carers who are social isolated. AnglicareSA’s dual community based Mental Health Respite service provides group activities for care recipients, whilst providing

opportunities for carers to attend to their own personal wellbeing and life goals, through social, educational, recreational and employment related opportunities.

Recommendation 4. Restorative residential respite models: to advocate for a review of the Aged Care residential respite system with a focus on restorative respite models.

Recommendation 5. Planned respite: to increase opportunities for planned respite within a residential facility with secure tenure, providing assurance and certainty for carers and care recipients; this is critical to carer wellbeing and sustainability.

Recommendation 6. Carer wellbeing supports: to include psychosocial carer supports which build on the social, emotional and community networks around carers and strengthen their informal networks.

1.1. Do you believe that the services proposed to be delivered at the national, regional and local level are targeted appropriately?

Streamlining Carer Access

AnglicareSA believes the services proposed for delivery at the national level are appropriate; however, we are concerned the majority of services proposed at the Regional Hub level are primarily offered via phone and online. This appears to de-emphasise the role of a Regional Hub as a place of connection and a physical community for carers to access supports. It also means carers may need to make 3 or 4 attempts via the national and regional levels, before being connected with face to face support.

Carers who are experiencing a crisis, especially those who live in a high risk environment and unable to contact police for a loved one, or are themselves elderly and physically frail will find it difficult to navigate the system by having to phone through to a national level rather than contacting a local service familiar to them and their situation. Evidence would suggest that the increased depersonalisation of individual services, may lead to carers preferring to push through emotionally, physically and mentally traumatic, isolating and difficult situations. This will be particularly evident with the older Carers who in AnglicareSA's evaluation suggested the overwhelming majority did not have computer access.

Efforts to triage and connect carers as soon as possible with face to face supports in their community is critical to ensure carers don't disengage after multiple efforts to make contact, re-routing and failure to connect with the support needed.

Recommendation 7. Streamlined supports: To reduce the number of contact points and time carers spend navigating supports by triaging calls and linking them to local services and face to face support as soon as possible. Local knowledge is important to optimally connect carers to local networks and resources.

Governance and Engagement - Regional Hubs and Local level collaboration

The carer experience and access to supports will be largely determined by how well Regional Hubs interact with and understand the challenges experienced by carers, care recipients, local services and community. This can be addressed through transparent governance processes, including carer and care recipient reference groups.

We propose a governance framework based on the state-wide Tasmanian Disability Gateway Service, which comprises two lead agencies and nine alliance partners who represent the sector and meet regularly to analyse strategic direction, operational effectiveness, review complex cases, troubleshoot solutions, identify cohorts in the community who are falling through the gaps, and develop collaborative engagement and service strategies. Operational since 2009, the Tasmanian Disability Gateway's values and purpose align with those of the ICSS; the Gateway's transparent governance processes have been central to embedding consumer voice, maximising customer supports and increasing visibility and access across community.

The intent to trial carer packages and broker fee for service based programs may impact the viability, sustainability and diversity of services, thereby, reducing choice and control and the quality of services carers can access. A strong governance framework will help ensure Regional Hubs remain aware of trends affecting service provision, and aligned with carer and community need.

Recommendation 8. Collaborative Governance Arrangements: for Regional Hubs to pursue joint governance arrangements with local community and service providers, ensuring strategic and operational alignment and a common understanding of priorities, resource allocation processes, and local need (The Tasmanian Disability Gateway's 2013 Evaluation demonstrates the effectiveness of a shared governance approach: http://www.dhhs.tas.gov.au/disability/projects/mid-term_review_of_disability_gateways).

Local Service Provision – Mixed funding models and Evidence based services: The trend to outcomes based funding, individual packages and user-determined funding includes many opportunities and challenges for the sector. AnglicareSA agrees with the principles driving these trends, namely to improve choice and control for customers, however, the impact on innovation and quality services is already apparent in NDIS, for example, poor viability of peer based group learning options mean group activities are contracting, with a trend to concentrate on more profitable individual interventions such as allied health.

In the interest of the long-term sustainability and success of the sector, we believe the transition to fee for service programs, individual packages and user-based funding in ICSS should be staggered, with a collective (government and sector) commitment to continuously review and assess the impact on services and customers. It is important to merge the supply side responses with user choice (demand) via robust mechanisms to ensure availability of respite, particularly in regional and remote communities. We also know many carer services operate on lean budgets and a high dependency on volunteers; innovative and carer-driven block funded programs have evolved over time (often 10-15 years); and, there is room for considerable improvement in particular domains such as aged care

residential respite. AnglicareSA believes the ICCS is well placed to build on the sector's collective wisdom, and analyse and advocate for the needed change identified.

Recommendation 9. Broker block funded and fee for service programs: to broker a mix of block funded and fee for service programs at the local level, informed by joint governance and decision making processes which includes carers and local carer support services.

Recommendation 10. Evidence based services: to create an evidence base of carer services which are currently delivered, have been co-designed with carers and provide an insight into 'what works', thereby, capturing the investment in carer supports to date.

2. A key factor in the effectiveness of regional hubs will rely upon their ability to understand the local service landscape and identify service gaps. If you were operating a regional hub, how would you undertake service mapping for your region?

AnglicareSA understands the needs of the communities it serves; recognising that locally based services delivered by those who live in and contribute to the community will translate into better outcomes for the people in that community.

AnglicareSA has a long history of collaborative and co-operative working relationships with numerous non-government organisations and local, state and federal government agencies (health, mental health, disability, housing, community etc.) and with the community. This is currently demonstrated through the Collective Impact approach, whereby community engagement and leadership involving community members, community organisations and other organisations and stakeholders work in partnership to achieve significant social change and create a sustainable and effective mechanism to engage and mobilise commitment into the future.

We believe that our fundamental purpose for partnering is to create added value, be it economic, environmental or social. AnglicareSA's partnering framework is built upon trust, transparency and a willingness to be open and honest in our communication.

AnglicareSA develops mutually respectful working relationships with business, community organisations and governments at all levels. Our engagement operates along a partnering continuum: Networking; Cooperation; Collaboration; Creative Partnering; and includes partnering with our customers and clients, other service agencies, stakeholders and corporate bodies.

AnglicareSA has developed a Stronger Partnerships Program which will assist with the identification and development of the most appropriate partnerships for ICSS. Our Stronger Partnerships Program supports AnglicareSA in the development of strong partnering arrangements that are fit for purpose, have clear mutually agreed expectations and responsibilities that provide added value and support the people within the partnership.

As indicated above, AnglicareSA's preference for operating a Regional Hub would be to engage key government and sector stakeholders through a joint governance process as 'Hub Alliance partners', creating a culture of inclusion, transparency and engagement from the beginning. We would work with Alliance partners to undertake stakeholder mapping, hold community forums and sector workshops with partners such as Carers SA, PHN, Alzheimer's Australia (SA), health, education etc, together with Carer workshops. We would also provide alternative options for carers to engage via post, online, phone surveys, face to face, one-on-one and in groups. As is practised in the Disability Gateway model, our service mapping would be captured and maintained in a live Community Action Plan which is regularly updated by the Hub Alliance partners.

2.1. How would you ensure that you had captured a complete view of the available supports for carers in your region?

AnglicareSA would undertake a range of one-on-one and group workshops with carer support services, carers themselves, specialist services across aged care, disability and mental health, as well as mainstream services across health, education and so forth. Community people, households, streets, neighbourhoods, schools and community centres are the epicentres of trends, needs and aspirations of communities. AnglicareSA actively listens to the voices of local individuals and groups to better meet their needs and aspirations. We have established many customer groups, who are culturally diverse and age diverse to ensure those who feel voiceless are heard, and we work to respond respectfully to their needs and aspirations in a manner that maintains the customer's dignity and integrity. A Carer Reference group will be key to embedding principles of co-design and accountability to carers and care recipients throughout the ICSS.

3. It has been identified that outcomes measurement will be essential for a future model. Outcomes measurement involves identifying how effective services are in achieving a particular objective. This commonly takes the form of a questionnaire which helps to assess aspects the carer's role. However, there will be a careful balance in measuring outcomes, whilst not placing undue burden on a carer to answer multiple questionnaires, particularly where they may be accessing more than one service. What are some ways that outcomes could be measured and these issues addressed?

The core focus of our business is engaging and improving outcomes and well-being for vulnerable individuals and families, strengthening communities, building strong partnerships, undertaking collaborative action and making use of strong evidence of what works. Our service delivery and planning identifies and builds on the strengths of the community, existing infrastructure of organisations, initiates networks and utilizes existing networks and resources to build a common

goal of improved outcomes and wellbeing for individuals and families that can be sustained into the future. This translates to a holistic service, with the clients welfare as the central point around which an individualised network of services is brought together to support them.

Our evaluation capacity is strengthened by our formal partnership with Flinders University through the Australian Centre for Community Services Research (ACCSR). The Centre undertakes research into social equity, social inclusion and social service and promotes best practice in community services and best value services to vulnerable individuals and communities.

Last year AnglicareSA commissioned the Australian Centre for Community Services Research¹ Flinders University to evaluate the ways that outcomes could be measured using tools which are:

- Quick & easy
- Valid & reliable
- Sensitive
- Free of charge
- Use without training
- Use with children
- Aligns with DSS' SCORE ratings

The Centre's research report evaluated 15 outcome measurement tools and recommended the Personal Wellbeing Index for a 'broad brush' generic tool as it met each of the criteria above and can be used across with people aged 5 and older. AnglicareSA is currently trialling the tool.

AnglicareSA recommends a co-design process between the national level, Regional Hubs and local services to implement outcomes measurement using PWI. This will enable a tiered outcome hierarchy which channel into customer/carer outcomes, and could include a range of tiered service level outcomes.

AnglicareSA has a 98% success rate when seeking feedback from our 200 Mental Health Respite carers; this high level of engagement is due to:

- Flexible feedback options: Individuals identify their preferred means of contact – many prefer via post and telephone as they are not connected to internet.
- Emphasis on continual improvement; acting on feedback to alter services and create a sense of influence and ownership by those involved.
- Consumer and service sector consultation: acknowledging the sector
- Inviting people to share their own case studies and propose suggestions to improve carer experiences.

¹ Iannos, M. & Goodwin-Smith, I. (2015). Developing a Client Wellbeing Index. Adelaide: Australian Centre for Community Services Research, Flinders University.

4. While this model will seek to help more carers, it will be important to ensure that quality services are being delivered. What would you view as the essential components of a future quality framework?

AnglicareSA believes existing frameworks should be adapted, drawing on the likes of the Standard Community Accreditation Framework, the Australian Safety Quality Framework for Health, Australian Service Excellence Standards, Aged Care Accreditation and quality review standards etc. Ideally, it would be developed through a co-design process with the sector, with an emphasis on avoiding duplication and building on existing quality frameworks. A customer feedback loop should also be developed and linked to the Carer Reference Group to drive continuous improvement.