

This discussion paper represents the views of members of **NSW Community Care Forum (CCF)**, as a part of its ongoing input to the redevelopment of the Commonwealth Home Support Programme (CHSP) and aged care reforms generally.

The CCF plays a key role in sector support. It brings together a range of stakeholder representatives working in community and sector development involved with in-home and community-based supports for older people, people with disability and their carers. Members include regional Sector Support and Development Officers, state-wide policy and development officers, non-government industry bodies and consumer peaks. The CCF meets six times per year to pool information, identify issues, monitor and respond to policies. It informs service providers and consumers through the membership networks of participating organisations and engages with, and provides advice and information to, key decision and policy makers in the following areas:

- Policy, planning, access and developments for older people, people with disability and their carers;
- Consultation structures and processes;
- Information strategies to promote and improve access;
- The allocation of resources for and within relevant programmes; and
- The relationship between programme areas and government jurisdictions.

Aged and Community Services NSW and ACT provides the secretariat support for the CCF.

**For further information:** Janice Poynton, [janicep@acs.asn.au](mailto:janicep@acs.asn.au)

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## **REFERENCES**

*Carers: Doing it Tough, Doing it Well* [Anglicare, 2016]

[https://www.anglicare.org.au/sites/default/files/Carers\\_Report\\_Digital.pdf](https://www.anglicare.org.au/sites/default/files/Carers_Report_Digital.pdf)

*Carer Recognition Act, 2010*

<https://www.legislation.gov.au/Details/C2010A00123>

*Carers NSW 2016 Carer Survey: Main report* [Carers NSW, 2016]

<http://www.carersnsw.org.au/Assets/Files/Carers%20NSW%202016%20Carer%20Survey%20Report.pdf>

*Give Us A Break! Evidence That Australian Carers Still Need Respite* [Carers NSW, 2016]

[http://www.carersnsw.org.au/Assets/Files/Give%20us%20a%20break\\_Evidence%20that%20Australian%20carers%20still%20need%20respite.pdf](http://www.carersnsw.org.au/Assets/Files/Give%20us%20a%20break_Evidence%20that%20Australian%20carers%20still%20need%20respite.pdf)

*Transitioning Australian Respite* [Social Policy Research Centre, 2016]

[https://www.sprc.unsw.edu.au/media/SPRCFile/Transitioning\\_Australian\\_Respite.pdf](https://www.sprc.unsw.edu.au/media/SPRCFile/Transitioning_Australian_Respite.pdf)

Other submissions to this Proposed Model:

- Illawarra Forum
- Carers Australia
- Sutherland Shire Aged Care Interagency

The CCF welcomes the opportunity to contribute to developing an Integrated Carer Support Services Program (ICSP) and make the following observations and recommendations.

### **The Focus of the Integrated Carer Support Service**

#### **Recommendation 1: That Carers as individuals in their own right should be at the core of the model.**

CCF members are concerned that the model described in the paper is centred on the system and the caring role, rather than the people it is supposed to assist.

The paper does not reflect, as it should, the *Carer Recognition Act 2010*<sup>1</sup>, which has ten key principles<sup>2</sup> that set out how carers should be treated and considered, policy, programme and service delivery setting. Statement 5 of the principles states that “*Carers should be acknowledged as individuals with their own needs within and beyond the caring role*”. It is therefore disappointing that the aims of the draft model focus on sustaining the *caring role*, rather than the carer as an individual with their own needs and issues.

CCF members believe the aims of the new integrated model are insufficient:

- To proactively support carers to sustain a caring role and avoid a crisis that might adversely affect or end it (e.g. information, training); and
- To provide support where carers are in, or at risk of crisis which might adversely affect or end it (e.g. emergency respite).<sup>3</sup>

The government’s commitment to the legislation should be detailed beyond *The services delivered by the sector would have links to legislative frameworks, such as the Carer Recognition Act 2010*<sup>4</sup>. Instead, the aims should be:

- To acknowledge that the relationship between a carer and the person they care for is valuable and complex;
- To respond to the unique and diverse circumstances and experience of individual carers;
- To support the human rights and choices of all carers to enjoy optimum health and social wellbeing;
- To recognise the value the social and economic contribution that carers make to society;
- To provide support for carers that is timely, appropriate and accessible; and
- To continuously engage with carers in order to learn from them and to make ongoing improvements to care systems and support for carers.

CCF members believe that this Model should reflect society’s respect and appreciation for the individuals who dedicate their lives to caring, often at great personal cost. Indeed, Carers NSW’ *Carer Survey 2016* found that more than one quarter of carers had been in their role for more than 20 years, and almost half reported providing more than 70 hours of care per week (including a significant proportion who considered their role to be 24 hours a day, 7 days a week)<sup>5</sup>. Not only do these findings highlight the major role carers hold within the community, more extensive caring demands were associated with an increased prevalence of long-term illness or disability.

This Model must be carer-centred and responsive to the needs of individuals, both current carers and former carers<sup>6</sup>.

### **The Resourcing of the Integrated Carer Support Service**

#### **Recommendation 2: That all carers can access the supports that they need when they need them.**

CCF members are concerned by lack of clarity in the future funding of the model, including assumptions of carer support aspects of aged care, disability and mental health programs<sup>7</sup>, which are more about cost-shifting than integration to improve ease of access. Many of these are false assumptions, because they have failed to take into account the current reform in each of those sectors, including the move to individualised funding for the care recipient. Ironically, these reforms largely depend on the presence of carers and the savings to government spending that are created by informal supports in the lives of people with disability and older Australians<sup>8</sup>.

<sup>1</sup> <https://www.legislation.gov.au/Details/C2010A00123>

<sup>2</sup> At Appendix 1

<sup>3</sup> Pg 19

<sup>4</sup> Department of Social Services: *Designing the new integrated carer support services – A draft Service Concept for the delivery of interventions to improve outcomes for carers* Pg 28

<sup>5</sup> <http://www.carersnsw.org.au/Assets/Files/Carers%20NSW%202016%20Carer%20Survey%20Report.pdf> Pg 6

<sup>6</sup> See the carer contribution in Rec 3.

<sup>7</sup> See highlighted as *Services the integrated carer support service would link to but not fund directly* on pg 11

<sup>8</sup> “If you can’t sustain carers into the future the entire system will collapse,” <http://www.abc.net.au/news/2016-12-05/carers-needs-not-being-met-under-ndis-anglicare-report-says/8091352>

The Model assumes that funding for carer support services will continue to be provided in the ageing and disability space. However, recent reforms have put carer support services at significant risk, especially respite [see Recommendation 3]. Key elements of the Model also rely on national systems that are not yet bedded down. For instance, CCF members are receiving mixed reviews from carers on the ground, who are having difficulty navigating the first phase of the Integrated Carer Support Service, and CCF notes that The Carer Gateway has not been subjected to an independent evaluation.

CCF also questions how the model will be funded. In 2014-15, the Australian Government spent \$170.219 million to provide carers with access to information, education, respite and counselling through a number of funded programs<sup>9</sup>. As a result of the aged care and disability reforms, a number of these carer-specific funding streams have already moved, or are moving, to My Aged Care and or NDIS, or will cease. Examples in NSW include the Older Parent Carer Program and Mental Health Respite: Carer Support. It is not realistic to think that community based programs can be sustainable without an adequately resourced carer support system which guarantees base funding.

CCF members are particularly alarmed that some elements of the Model appear to expect income generation to replace core funding and/or retrospective payments to providers. Suggestions that the system become self-sustaining are unrealistic and threaten the viability of vital supports for carers. These include the following references [with highlighting by CCF]:

- *(the National Education Initiative and National Carer Counselling) program could be delivered as a **fee for service arrangement***
- *(Regional Hub Program), however would likely be delivered on a block funding basis (**at least initially**)*.<sup>10</sup>

The Model also states that the Regional Hubs will have a linking role and refer carers to external services not funded by them, and that there may be a fee for the services<sup>11</sup>. This is a concern as many carers experience financial difficulty and may prioritise services for the person they care for, not themselves.

Considering that Access Economics estimated that if informal carers were no longer available, the replacement value of these unpaid care hours would be \$60.3 billion<sup>12</sup>, CCF members believe that it makes good financial sense for the Commonwealth to fund this system.

### **Key Components of the Integrated Carer Support Service**

#### **Recommendation 3: That Planned Respite for carers be specifically funded.**

CCF is very concerned by the lack of attention to detail regarding respite in the Model, both in terms of access and eligibility, which are directly related to outcomes for individual carers, and future resourcing. It fails to acknowledge the integral role in carer support of providing respite as a break for the carer, which is not only a physical break, but an emotional one, a chance to re-charge. It is important that carers can have confidence that the person for whom they are responsible can receive quality care in-home and away, both for planned breaks and in emergency situations.

This omission defies recent evidence from research projects by Carers NSW, Anglicare Sydney and the Social Policy and Research Centre that respite is in demand and supports carer wellbeing<sup>13</sup>. If carers do not get enough of the right kind of respite in the medium to long term, it may very well cause a breakdown of caring relationships which would ultimately lead to significant cost pressures across all three systems to provide substitute formal care.

In terms of presence in the Model, the criteria to access short term (for attendance at activities such as education, peer support or coaching)<sup>14</sup> and emergency respite (needed within 24 hours) appears to be limited and needs to be expanded. Also, respite is not linked to improved health and wellbeing of the carer as a primary goal, but rather to participation in set activities within the Model.

The Model also talks about *leveraging existing community care relationships and infrastructure*<sup>15</sup>. It assumes that planned respite will remain unchanged in the future and continue to be funded outside the carer programs delivered by DSS<sup>16</sup>, overlooking the very real risk that carers' access to planned respite in the future will fall between the carer support and formal care systems.

<sup>9</sup> *The model has not been finalised, nor agreed for implementation by Government. However, the following existing programs are in scope for transition in full, or in part\*\* to a new integrated carer support service.* on pg 28.

<sup>10</sup> *How will this model be funded? Block funding, fee for service, or a combination of both?* on pg 31

<sup>11</sup> The infographic on page 11; At a local level 2.3, 4.3b 5.4b and 8.3c

<sup>12</sup> Deloitte Access Economics utilised data drawn from the Australian Bureau of Statistics Series B population projections to estimate the number of informal carers. This was mid-level population projections corrected for factors such as births, deaths and net migration into Australia.

<sup>13</sup> Give Us A Break! Evidence That Australian Carers Still Need Respite [Carers Australia NSW, 2016]; Carers: Doing it Tough, Doing it Well [Anglicare, 2016]; Transitioning Australian Respite [UNSW Social Policy Research Centre, 2016]

<sup>14</sup> Pg 24

<sup>15</sup> Pg 9

<sup>16</sup> footnote 3 on pg 15

Indeed, CCF members believe it will be important to ensure interface between the carer and aged care systems so that expectations of each program area are clear and carers are not to be bounced between the two. CCF members have received feedback from carers about difficulties with My Aged Care (MAC), including:

- MAC call centre staff focusing on care for individuals over 65 years only and failing to acknowledge carers' need and/or refer them to the Carer Gateway; and
- service providers have reported that there has been a considerable drop in the number of referrals for respite since the introduction of MAC screening and Regional Assessment Services conducting assessments for access to CHSP.

Flexible and centre based respite for carers of older Australians, including overnight cottage respite, currently funded under the Commonwealth Home Support Programme (CHSP) are in scope to be merged with the Home Care Package Programme (HCP) from 2018. These packages do not specifically include services for carers, although the functional assessment may allocate services to an older person that might render a respite effect, if the timing is suitable for the carer.

Similarly, for carers of people with disability, there are no funded carer-focused support services under the NDIS, including respite, even though social participation services may give the carer a respite effect provided that timing works for the participant and the carer:

*Respite support for carers is not automatically included in the NDIS package of the person they care for<sup>17</sup>*

At a recent consultation in Eastern Sydney, carers advised that they specifically need access to planned overnight respite, which does not fit with any service description in the *NDIS Price Guide*. This type of respite allows carers to continue to support individuals with relatively high needs by providing a regular block of respite of 12 to 24 hour duration. CCF members also believe that many carers use respite funded under the NSW Community Care Supports Program (CCSP) for people with disability under 65 years<sup>18</sup> as their only support, even though their needs are significantly greater. There is no equivalent to CCSP respite in the NDIS.

Furthermore, CCF notes that NSW Government funded respite packages in some areas have already ceased in anticipation of the NDIS transition; this has left carers with only access to emergency respite through the Commonwealth Carelink program, which of course is in scope for replacement by this Model.

CCF members therefore suggest that respite should be funded within the carer model of support, in order to separate and equally value carer and care recipient outcomes at the policy/departmental level<sup>19</sup> and the operational level<sup>20</sup>, and remove unnecessary hurdles or obstacles for carers to receive the support they need.

This requires establishment of a funding stream in the Model consisting of:

- CCSP respite and other State funded disability respite;
- CHSP respite and other Commonwealth funded disability respite;
- Mental Health Respite: Carer Support; and
- any other National or State based carer support programs.

## **Structure of Regional Hubs**

**Recommendation 4: That the Regional Hubs are rolled out in a logical way to reflect the demographics and needs of carers in their communities.**

CCF members are concerned that the entire Model is in danger of becoming centralised and of poor service to the needs of the majority of carers if the Regional Hubs are too few, too large and/or formed without community ownership. The vital networking and linking functions of the Hubs rely on a community presence and relationships of trust with both carers and other service providers, including:

- Understanding of the community care landscape affecting carers [eg. NDIS rollout schedule];
- Knowing what is available to carers, based on their profiles and needs [eg. understanding eligibility criteria];
- Maintenance of current data base of relevant services for referrals [eg. wait lists];
- Connections with TAFE, RTOs and other sources of education and speakers for support groups [eg. local Outreach Workers];
- Considering and respecting what carers and caring means for Aboriginal and other diverse communities [eg. work with local Elders and CALD leaders];

<sup>17</sup> <http://www.smh.com.au/national/carers-falling-through-the-cracks-under-ndis-20161201-gt1ufu>

<sup>18</sup> Formerly the HACC Program

<sup>19</sup> ie. DSS & DoH

<sup>20</sup> ie. Carers Gateway/Regional Hubs and MAC/NDIA

- Ensuring location and timing of scheduled activities and events to fit within a community context [eg. liaise with Councils and other community workers];
- Negotiating carers' access to other programs [eg. respite providers, including residential aged care operators];
- Educating about, and advocating for, carers in other systems [eg. Local Health District]; and
- Promoting carer support to carers, 'hidden carers' and referrers.

It therefore comes down to a question of logistics. For a Regional Hub to succeed they need to have staff attend all relevant interagency meetings and be active within established community networks.

Regional Hubs should not contradict existing structures and hubs that have formed naturally in practical response to communities. CCF members believe that the concept of 'region' should preferably start with the geographic divisions used for the My Aged Care system of Regional Assessment Services (RAS), overlaid by a measure of population size. For instance, the region of South East Sydney has 1,013,739 people within a 546 square kilometre area<sup>21</sup> and always been divided into two sub-regions [Sutherland/St George and Eastern Sydney/Inner City] and would therefore require two Regional Hubs for carer support<sup>22</sup>.

CCF members also believe that the appropriate make-up and management of Regional Hubs will be crucial to their success in connecting with communities and individual carers.

The Regional Hubs should build upon systems, skills and experience, not create new ones. They should provide no less to carers such as Helen Mabbutt than what they have now:

*I am concerned about the quality of future service delivery to carers. Local organisations who currently provide services have staff who have experience and networks built from years of work in their area of expertise. I am very concerned about what will happen to this local expertise under the proposed regional hubs. When my son [now 15] was at pre-school, the Department of Social Services changed the service provider assisting the pre-school with his learning program. A local service provider was replaced by a larger interstate provider and as a result my son lost access to the educational support. I took my concerns to the then Minister, Mr Mal Brough, who acknowledged my son had lost a needed service under the new contract arrangements.*

*The current service provider I access for carer support is the Sutherland Shire Carer Support Service. I have had contact with this service for nearly a decade. In particular, I am concerned that the valuable knowledge and expertise residing in the Sutherland Shire Carer Support Service team, will be lost if they are no longer the preferred local service provider, under the governance of the new regional hubs. There is no substitute for a thorough understanding of local conditions and networks, built over time. This sort of expertise is irreplaceable. At the heart of carer service provision is confidence in the service provider. Over years of access to the Sutherland Shire Carer Support Service, I have developed confidence in the[ir] service provision. Under a new service provider that confidence would have to be built again.*

The Regional Hubs should reflect the diversity of the communities which they aim to serve and enable culturally diverse carer support delivery, featuring no one denomination or dominant culture.

CCF urge that the Model adapts the Victorian approach for governance of child protection services in a given region. Instead of appointing a head contractor or mandating a particular approach, the Victorian government invited all child protection service providers to come together to form a unified governance structure that would best reflect:

- differing needs across sub-regions;
- needs of different population groups [eg. mental health carers, disability carers and ageing carers, older parent carers, carers of children with disability];
- operational (service delivery) issues [eg. staffing, travel]; and
- a coordinated approach between service providers utilising each organisation's unique skills.

Such an approach may be achieved by formation of an umbrella organisation that:

- administered funding;
- render governance; and
- coordinates activities.

As the Model indicates that there will be a tender process, CCF members also urge the Department to give careful consideration to potential conflicts of interests, particularly as Regional Hubs will provide *eligibility assessment, coordinate access to respite and targeted financial support*<sup>23</sup>.

<sup>21</sup> See demographic breakdown at Appendix 2

<sup>22</sup> 4% of Australia's 1,896,852 carers live in South East Sydney

<sup>23</sup> Pg 8



## Appendix 1 - The Statement for Australia's Carers

- 1 All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
- 2 Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
- 3 The valuable social and economic contribution that carers make to society should be recognised and supported.
- 4 Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
- 5 Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
- 6 The relationship between carers and the persons for whom they care should be recognised and respected.
- 7 Carers should be considered as partners with other care providers in the provision of care, acknowledging the unique knowledge and experience of carers.
- 8 Carers should be treated with dignity and respect.
- 9 Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
- 10 Support for carers should be timely, responsive, appropriate and accessible.

## Appendix 2 - Profile of South East Sydney RAS Region

Sub-region	SUTHERLAND SHIRE	ST GEORGE AREA	EASTERN SYDNEY / INNER CITY
Local Government Area coverage...	Sutherland Shire  =369 km <sup>2</sup>	Georges River 38 km <sup>2</sup> + Rockdale 28 km <sup>2</sup>  =66 km <sup>2</sup>	Botany Bay 27 km <sup>2</sup> City of Sydney 27 km <sup>2</sup> + Randwick 36 km <sup>2</sup> + Waverley 9 km <sup>2</sup> + Woollahra 12 km <sup>2</sup> =111 km <sup>2</sup>
Total population...	  =226,220 people <sup>24</sup>	Georges River 147,906 <sup>25</sup> + Rockdale 109,862 <sup>26</sup>  =257,798 people	BB 46,587 <sup>27</sup> + CS 205,339 <sup>28</sup> + R 145,822 <sup>29</sup> + W 72,699 <sup>30</sup> + Wo 59,307 <sup>31</sup> =529,754 people
Carers providing unpaid assistance to a person with a disability, long term illness or old age; above the average for Greater Sydney area of 10.8%	20,534 carers [12%]  =20,534 carers	Georges River 12,656 [11.4%] + Rockdale 8,376 [10.9%]  = 21,032 carers	BB 3,349 + CS 9,979 [6.3%] R 10,237 [9.4%] W 4,648 [8.7%] Wo 4,442 [10%]=32,655 carers
Aboriginal population...	  =1,740 First Peoples	Georges River 717 + Rockdale 574  =1,291 First Peoples	BB 615 + CS 2,185 + R 1,844 + W 242 + Wo 114 = 5,000 First Peoples
People who were born in non-English speaking countries...	20,333 [9.6%] people  =20,333 people	Georges River 49,905 [37%] + Rockdale 37,737 [39%]  =87,642 people	BB 14,091 [36%] CS 50,933 [30%] R 34,962 [27%] W 11,674 [11%] Wo 7,625 [15%]  =119,285 people
People who reported difficulty speaking English...	  =2,531 CALD people	Georges River 12,923 + Rockdale 8,158  =21,081 CALD people	BB 2,873 CS 8,313 R 4,975 W 1,159 Wo 496 = CALD people

<sup>24</sup> Estimated Resident Population 2015 <http://profile.id.com.au/sutherland/about>

<sup>25</sup> <http://profile.id.com.au/georges-river>

<sup>26</sup> <http://profile.id.com.au/rockdale>

<sup>27</sup> <http://profile.id.com.au/botany-bay>

<sup>28</sup> <http://profile.id.com.au/sydney>

<sup>29</sup> <http://profile.id.com.au/randwick>

<sup>30</sup> <http://profile.id.com.au/waverley>

<sup>31</sup> <http://profile.id.com.au/woollahra>