**A draft Service Delivery Model for a proposed new carer support service system**
**https://engage.dss.gov.au/a-new-integrated-carer-support-service-system/**

This discussion paper represents the views of members of **Sutherland Shire Aged Care Interagency (ACI)**.

ACI membership is comprised of funded providers of in-home and community-based care and supports under the Commonwealth Home Supports Program (CHSP), Home Care Packages (HCP) and other local professionals working for older people who need help to live safely and independently in their own homes, and their carers. Members include managers and co-ordinators of not-for-profit and private organisations and regional CHSP Sector Support and Development Officers; some services are unfunded. The ACI meets at least six times per year to share information, discuss aged care policy and reforms, and to develop joint solutions to systemic challenges.

The Sutherland Shire CHSP Sector Support and Development Officer (SSDO) project provides the secretariat support for the ACI.

**For further information:** SSDO, Melinda Paterson, melindap@acs.asn.au

**Note:**

**Sutherland Aged Care Interagency members reflected on the questions posed by the draft Service Delivery Model during December 2016, and had detailed discussions at a special consultation meeting on 6th December. Their responses to the core review questions are included in the submission by Aged & Community Services Australia (ACSA).**

**Below are ACI's 'Other Comments':**
**a. General Remarks About *The Proposed Model For An Integrated Carer Support Service***
**b. Specific Aspects Of The Proposed Model**

## a. General Remarks About *The Proposed Model For An Integrated Carer Support Service*

ACI members applaud the efforts of government to better understand the needs of carers and the use of consultation and co-design processes in designing a new carer support system for Australia. Unfortunately, this proposed model falls short of the promise made by this project, and stakeholders in Sutherland Shire are very disappointed. Carers, carer support professionals and general aged care providers alike believe we have been speaking loudly and consistently for several years[1] about the need for **local, community-based carer support services**, but the model ignores this.

We have described time and again a 'hub and spokes' model, in which a small proportion of funding goes into a centralised system of public education about issues of caring and as a touchpoint for those who don't know where to start when their caring journey begins, including people who don't yet define themselves as 'carers' [ie. the hub]. However, it is local services [ie. the spokes] that will provide access to the bulk of supports needed by carers – the community centre clearly visible in the local shopping centre, the friendly face when carers visit who is the same familiar voice on the other end of the phone and the highly skilled and experienced carer support professional who runs relevant activities with other carers, peers, friends and confidantes. This is where the bulk of resources should be allocated – on people, not technology. Technology is a basic enabler only.[2]

Ann, a local carer, gave some of her ideas in the hope they *"can help someone else":*

> *"I know the world is changing and most things now can be done online but a lot of older carers won't be comfortable going online and filling out forms and answering questions. An older person would be more comfortable sitting talking to someone face to face or chatting over the phone."*

Indeed, ACI members believe the National Service Infrastructure Program is more about meeting the needs of government and the system, rather than supporting carers. Even though the model indicates that carers do not have to register nationally to get services, they do have to get an online account and a National Carers Record. Experience tells us that both will be disincentives to many carers, including those from Aboriginal and trauma backgrounds; we told you this in the last consultations.

Beverley is a typical carer who offered her feedback on the model:

> *"As I am 75 years old, and computer literate, I prefer face-to-face with communication and groups. Online one cannot see the body language, especially in a counselling situation."*

The carer support system must be **a human service** that values all carers and is sufficiently resourced to respond appropriately to every carer who needs help, as stated in the principles of the *Carer Recognition Act 2010*[3]*:*

Schedule 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.

[1] In fact, since consultants for the previous Australian Government started asking us.
[2] ACI members question the assumptions on pg 7 of carer comfort and cost efficiency; online tools are very expensive and prone to technical problems [eg. Census, My Aged Care portals are down constantly].
[3] https://www.legislation.gov.au/Details/C2010A00123

The carer support system must reflect the fact that **caring is a complex relationship**, filled with feelings of love, duty, respect, fear, pain and hope, not simply a set of duties that can be replaced by external/formal 'services'. There is a fundamental flaw in the assumption of this proposed model that the caring role will be reduced and supports increased by aged care and disability reforms:

> *The Plan is intended to complement the significant investment made in the reforms in other sectors, including aged care and disability, aimed at providing better support for many Australians.*[4]

The Australian Bureau of Statistics (ABS) in 2015 estimated that there are almost 2.7 million Australians caring for people with a disability, frail aged or people with chronic illnesses, with around 850,000 (32%) identified as primary carers, and formal services will certainly not change the relationship for the 79% of carers who reside with the person they care for twenty four hours a day, seven days a week. ABS found 71% of primary carers lived with at least one person with a profound core activity limitation (ie. someone who always needs help with a mobility, self-care or communication task); 67% said they were motivated by a family obligation and 44% felt an emotional obligation to care[5].

The reality of reform is that the National Disability Scheme (NDIS) and Consumer Directed Care (CDC)/Increasing Choice reforms in aged care are creating new, additional demands on carers, such as navigating the system for/with the person they care for, providing financial management for/with them and sometimes care co-ordination which used to be done by a professional, funded case manager. ACI members agree with assertions by Anglicare, in their recent report on carers and the NDIS that this model fails to provide what is being lost from the carer support landscape:

> *While the current role of some carers may well diminish under the new system, there is no doubt that informal, long-term care provided by carers will continue to be a major pillar of the care system for people with disabilities. The challenge in the new system will be to ensure that sufficient supports and consequent benefits will continue to flow to carers, to support them in their ongoing role.*[6]

ACI members recommend local, community-based carer supports follow the same principles as outlined by the Australian Productivity Commission report, *Caring for Older Australians* in 2011; that is, "low intensity" supports that can be accessed directly, without requiring carers to divulge lots of personal information straight away. Carers should have time to try supports and groups before registering for higher intensity services for themselves [eg. respite] or the person they care for [eg. personal care, domestic assistance, home modifications].[7]

We respectfully suggest a re-wording in the description of this model to get it right:

> *Delivering services ~~through national platforms~~ locally enables improved access to supports for large numbers of people. It also provides a way for carers to seek preliminary support, before deciding whether to seek more intensive supports.*[8]

The Regional Hub should be community-based and reflect the geographical areas in which carer support currently occurs. In our area, for instance, carers are accustomed to Sutherland Shire and St George either separately or combined, but an area no larger than that. There a danger of hubs that cover too large an area will effectively become a centralised model, and the staff and operations too far removed from carers and the community.[9]

---

[4] Pg 4
[5] [ABS 2016]
[6] *Carers: Doing it Tough, Doing it Well* https://www.anglicare.org.au/sites/default/files/Carers_Report_Digital.pdf
[7] Similarly, in its submission to the Legislated Aged Care Review, ACI proposed a re-shaping of the Aged Care System which has a clear distinction between high intensity Aged Care services and low intensity Community Support suggested by the Australian Productivity Commission and informed by the community's experiences of the My Aged Care system since 2015.
[7] Pg 8
[9] Indeed, we encourage DSS to take a closer look at the depth of carer support services funded through the old HACC Program, which provided far-reaching impacts in terms of both outcomes for individual carers and the profile of carer needs and issues in the community generally; the assumptions in the paper about limited reach and lack of information-sharing sound like the CCRC model. Ours covered Sutherland Shire + St George + Eastern Sydney/Inner City.

ACI members are confident that our local demographics clearly justify the creation of **a single Regional Carer Support Service Hub**:

- Sutherland Shire Local Government Area covers 369 km$^2$, with a total population of 226,220 people[10]
- Sutherland Shire has a significant Aboriginal population of 1,740 First Peoples
- Sutherland Shire is culturally diverse [17.3% were born overseas, 9.6% in non-English speaking countries[11]]; 2,531 reported difficulty speaking English[12], CALD communities are smaller than the Sydney average and isolated from CALD centres
- 20.7% of the population were aged 60 years and over [compared with 18.0% for Greater Sydney; Sutherland Shire also had *larger* percentage of 'Seniors' (8.3% compared to 7.2%)[13]
- There were 20,534 carers providing unpaid assistance to a person with a disability, long term illness or old age in 2011; at 12% of the overall population, this was above the average for Greater Sydney area of 10.8%[14]
- Activus [formerly Sutherland Shire Community Transport] has 3,500 clients on books; 40% of them have a carer

Many of these carers are known to, and supported by, Commonwealth Home Support Programme (CHSP) services, including *Counselling, Support Information and Advocacy - carer support,* which is in scope for transition to this model[15], but will not apparently be block funded:

- Sutherland Shire Carer Support Service (SSCSS) has over 800*[16] carers on their mailing lists, including 7 part-time staff and runs specific programs for carers of people with dementia, former carers, mixed carers and consumers, older male carers, CALD carers (Greek, Chinese and Spanish speaking backgrounds).
- Catholic Care Dementia Carer Support Service has 100 active carers, with only one staff to do groups and meet with carers.
- Advance Diversity Services [in St George] supports around 140* CALD carers; bilingual staff provide programs for Macedonian, Chinese, Greek, Arabic, Italian Carers through Carers support groups and other languages on an individual basis.
- 3Bridges Community [in St George] supports around 100* carers.
- Kurranulla Aboriginal Corporation supports indigenous carers across Sutherland Shire and St George.

If these local services do not receive block funding or a guaranteed level of brokerage funding allocation from a Regional Hub, they will no longer exist. ACI members strongly believe that, without these expert local providers, if they have to rely on the centralised hub proposed in this model, carers in Sutherland Shire will not have access to the **essential components of a quality carer support service**:

- Accessible for all groups of carers
- Approachable, friendly, helpful, empathic and caring staff who 'get' the carer experience
- Engendering trust
- Accurate information given
- Consistent, open response to concerns, complaints or compliments
- Prompt response times to phone calls, referrals, emails, requests for information
- High quality services, eg. support group facilitation, advocacy, assisted referrals
- Consistent positive feedback from carers
- Training of staff in carer issues, group work, grief and loss, dementia and disability education

ACI members believe that quality is best achieved through direct funding of local, community-based carer support services.

**ACI is confident that this model will be successful, because it recognises and builds on existing skills, expertise and social capital in the community and puts carers at the centre, not the system.**

It is essential to engage with each carer at the start of their journey. If things go wrong here at step one, they will never be right.

[10] Estimated Resident Population 2015 http://profile.id.com.au/sutherland/about
[11] http://profile.id.com.au/sutherland/birthplace?
[12] http://profile.id.com.au/sutherland/speaks-english
[13] http://profile.id.com.au/sutherland/service-age-groups
[14] http://profile.id.com.au/sutherland/unpaid-care
[15] Pg 28
[16] [*includes CCSP disability]

ACI urge the designers of the integrated carer support system to **be informed by carers** who generously shared their personal stories for this submission:

***"Through the local groups in the Sutherland Shire I have gained, among other things, the best way to***
***respond not only to my husband's changes (in personality and behaviour), but to others who are scared of the diagnosis, don't visit anymore and are judgemental.***

***My knowledge and experience of dementia was very limited. I thought that you lose your memory and slowly fade away and that was it. Boy, how wrong I was.***

***These groups have connected us with Alzheimer's Australia NSW to attend their wonderful and informative workshops. We were involved in their digital media awareness raising project "Courageous Conversations". Anything to help raise awareness nationally.***

***In a dementia group situation each carer comes with their own specific story. This helps when a question is asked as to how others manage and cope, not only with their loved one but the mountain of paperwork that needs to be done.***

***I cannot describe the relief I feel when sitting in a room of people who are going through the same thing, and experiencing the same hardship. I have drawn strength from them as well as the group leaders. It has been amazing to be able to share stories and not have to explain anything because everyone in the room gets it. We can share things and make jokes without being judged. To be able to be myself to cry, yell or swear is so stress releasing. To have a group of people to share this hell with it invaluable."***

**- Beverley Weston**

***"I am the carer of a 15yr old boy with complex special needs including an intellectual delay, autism, ADHD and Sensory Processing Disorder and a resident of the Sutherland Shire. As a carer who has actively sought out services and support for my child since he was a pre-schooler, I read with interest the Discussion Paper…***

***I am very concerned that the creation of new "regional hubs" will not lead to better service delivery than the networks currently available. The experience of the creation of new "hubs" for service delivery for Medicare, Centrelink and Roads and Maritime Services in Sutherland Shire has seen reduced accessibility to services. Existing offices were closed and concentrated into "hubs" which mean more people have to travel further and wait longer to access a service face-to-face. This has been my experience with Medicare. I have to travel further and the wait times have increased. This also impacts my son if he is with me. He needs constant supervision and finds waiting very challenging.***

***"Hubs" have not made life as a carer easier for me. I associate "hubs" with cost cutting and reduced face-to-face service delivery. Service delivery is becoming "self-service" which is not suitable for everyone all of the time. Face to face contact may be the preferred mode of service delivery for people who don't have access to or the skills to use computer technology, or prefer not to. Persons with some cognitive and emotional disorders benefit from face-to-face service delivery. Age related impairments also mean that face-to-face service delivery is necessary."***

**- Helen Mabbutt**[17]

[17] Helen is also concerned about loss of quality in carer supports. See the submission by NSW CCF for her words about that issue.

## b. Specific Aspects Of The Proposed Model

### THE IMPORTANCE OF UNDERSTANDING CARERS

- carer support is not a simple, linear process; *"It is unrealistic to expect programs to 'fix' carers so they go away and don't need anything ever again"*
- caring is rarely planned and usually starts within a period of high family emotion; *"Peoples worlds can turn upside down in a day if one of them has a stroke etc"*
- having to provide personal information to strangers is a disincentive for many to seek help; *"It's good that carers don't need to register at a national level, but the digital carer account will sound much the same to a carer, as does the National Carer Record"*
- quality carer support is accessible, approachable, friendly, and with caring staff who carers can trust to give them accurate information and a prompt response; SSCSS ring the carer back the same day *"if they wish to talk for an hour that is what you do"*
- the calibre of call centre operators is not appropriate for the nature of calls from carers who may be distressed; *"It's hard to ask for help and share the secret pain of your family"*
- *"It's hard to hand your loved one over to a system"*
- it is vital that carers have a local place to go in times of stress; *"Just feeling better and feeling understood is an important outcome!!"*

### THE MODEL

- the focus is on the 'how to', not on what is needed by carers; this is another example of government seeking cheap consistency at the cost of specialist skills and unique skills required for individual, human responses to complex situations
- the online account sounds like the Coles self-service process; it is meant to be quicker and easier, but does not work out that way in practice
- the designers in government have not listened properly to what the sector and carers are consistently telling them about the positive impacts of community-based carer support services, and have preconceived plans
- the 'hub and spokes' concept has been the focus of community recommendations since consultations by the previous government; this model has done the hub, but lost the spokes
- accuracy of information is a problem in centralised models and not well-targeted to carers' needs on the ground**;** SSCSS has local knowledge and information received at Interagencies about what is happening at a federal level or with NDIS
- it is a false assumption that centralised creates value for funding; SSCSS is reaching many more people than they are resourced to reach
- community-based providers attract and retain workforce; local carer support services have long term employees as compared to carer respite centres, who have a high turnover
- existing local carer support services are known and trusted; a provider talked of helping a carer who was overwhelmed by the amount of paperwork she needed to complete and SSCSS were available to help
- this model is not sustainable; *"they will find out it does not work and reinstate the existing model, but all the experienced services and staff will be gone by then"*
- it is vital to minimise the entry processes for carer support and make it easy and instantaneous for carers to talk to someone who is understanding; based on the experiences of My Aged Care and the Carers Gateway call centres, carers and providers are suspicious that government does not want this to work
- providers said that it looks like "*the gate is closed"*, because the access points are acting as 'gatekeepers' and not talking to each other; ACI received an email from a carer [who is very articulate and also on several Boards] who spent 26 minutes on the phone to My Aged Care, which he described as *"an idiotic system wasting time and money"* answering questions, being told he is ineligible for the carer support service he was requesting [which is incorrect] and that they were not listed on the data base [also incorrect]
- has the Carer Gateway been evaluated? no one here uses it, and MAC is also turning people off seeking help; the service directory information is not easy to navigate and the call centre staff are unskilled for the intuitive, flexible and responsive support that carers require
- it is a great concern that they suggest use of volunteers, carers and former carers to deliver the services; fears that this will not produce quality and is motivated more by cost-cutting and the overall strategy to get carers back into the workforce
- a professional managed support group can assist the carer to gain strength through shared stories; support groups give carer the freedom of a safe place where they can make jokes, make light of their situation and speak without judgement
- where is the support for former carers in this model?; the emotional strain of caring does not suddenly leave when the carer loses the responsibility for the person they care for [and the former carer needs more than direction into employment]

- education in the model seems to focus on existing mainstream TAFE, training by RTOs etc, which is not carer support specific; carer support services provide education to assist carers with their caring roles [eg. cooking, first aid] and in a carer friendly environment [eg. short courses, school hours, with respite provided][18]

**REGIONAL HUBS**

- *Carers will be able to access <u>most</u> supports through contact with a regional hub*[19]; this should say 'all', as this is a human service and must be accessible to all
- the size and number of regions will determine their success; building relationships is not practical if regions are too large[20]
- Sutherland Shire should be a regional hub; it is a huge area (369 $km^2$) and has an old and ageing population [see main submission]
- will carers need to register with the hub?
- funding a new player would be a horrible waste of resources and create a gap in carer support: a new provider would need to spend at least 3 months recruiting staff and mapping local services before they could make reliable referrals; it will take much longer to gain the community trust that existing carer support services already have
- the suggestion that they will subcontract to local providers is not viable; subcontracting adds overhead costs to service provision and hubs will always use their own organisations' staff
- local carer support services are seen as competition to peaks and centralised hubs; they therefore rarely receive referrals from the Commonwealth Carer Respite Centre (CCRC) or Carers NSW

**RESPITE**

- it is incorrect to assume planned respite will be available in as part of recipients' services; HCPs often don't even cover the basic aged care needs of the care recipient and respite does not exist under NDIS
- how can you pre-register for emergency respite?
- even now, the service system is not sufficiently resourced to meet the respite needs of carers; one provider of CHSP and HCP reported that they are pooling the profits from their private services to fund emergency respite
- we support Carers Australia NSW' fact sheet on the need for respite at http://www.carersnsw.org.au/Assets/Files/Give%20us%20a%20break_Evidence%20that%20Australian%20carers%20still%20need%20respite.pdf

**USE OF TECHNOLOGY**

- how many carers actually have a computer, let alone the time and energy to use it to establish an online account?; accessing complex information and personal support in a crisis is very different from doing an occasional Google search for directions or making a restaurant booking
- there is still a platform for the web, but it is too early for so much emphasis on it in the model; *"they are looking at the next generation – they are looking 20 years ahead"*
- how many carers can navigate the Carer Gateway, when providers who 'speak the lingo' have trouble?; several providers reported searches of the online directory which only produced irrelevant and out-of-area responses
- looking is not the same as accessing, and inaccurate information and tools are very dangerous for referrals*;* providers said that they risk losing credibility when promoting the Carer Gateway
- carers are human beings dealing with difficult and challenging situations, which are often complex and highly distressing; they should always have access to a human response
- literacy cannot be assumed; some carers are not literate in either English or the language of their birthplace, if from a CALD background and/or have print communication difficulties associated with their own age or disability
- the 'digital carer account' sounds very cold and impersonal; there are more carers who would struggle to access this, than not, due to language, culture, difficulties with technology and emotional exhaustion

Thank you for this opportunity to comment on the carer reforms.

[18] Note also that local Training Projects which have been block funded through CHSP have sometimes assisted with this, but they are also unlikely to survive the aged care reforms.
[19] Pg 26 *[5. About how carers might experience the model]*
[20] Please see the detailed discussion in the submission by NSW Community Care Forum, which uses our area as a case study.