# Sutherland Shire Carer Support Service Inc.

## Response to Draft Model of Integrated Plan for Carer Support

- It appears that in the draft model that resources will be concentrated at the Regional Hub level. Very little (if any) face to face interaction with carers will occur at this level; it is the job of local service providers to give information and advice, facilitate peer support groups and provide counselling, education and training, coaching and mentoring. Given the move to a competitive tendering environment for community services, how will DSS ensure that the Regional Hubs actually do thorough service mapping and fulfil their obligation to subcontract local face to face carer support to the most appropriate, skilled and experienced local providers?
- It is incorrect to assume that cutting block funding to local services will result in cost savings. If the model changes to one where Regional Hubs subcontract to local providers, this is likely to result in excessive charges and extra administrative costs as the local subcontractors will have to charge as much as they can to stay viable.
- The size of “regions” in the definition of Regional Hubs will be critical to the effectiveness of the model. We would suggest that regions be smaller than LHDs so that the Hubs can do effective service mapping, networking and accurate information giving to carers.
- The model assumes that local service providers will continue to exist, without DSS funding and with funding from other sources. How can DSS be sure that this important local component of the model will still be there, without block funding and with local service providers at the mercy of the Regional Hubs?
- In rural and regional areas there may be no local service providers, or very little choice of providers. How will the 3-tier model operate if there are no services available at the local level?
- Given that carers have been identified as a population group with very low levels of wellbeing and potentially high levels of social isolation, the model needs to commit to continue block funding local agencies which can respond to the unique needs of the carers in their geographical area.

**Here are some quotes from local carers who wish to comment on the Draft Model:**

“The reason why Sutherland Shire Carers Support Group works so well is that you keep it Simple. All it takes is one phone call and you can talk to someone who is able to help you sort out your problems. Sometimes when a carer is having a bad day or having problems with the person they care for. They need to talk or cry to someone with understands and can help them straight away. Whether it's over the phone or face to face in a meeting at the office. OR in a support group with people going through the same problems as you. Carers having a problem, don't have time to send an email or wait in a phone queue then wait for someone to get back to them with an answer. Everything a Carer needs has to be in one place, that is quick and easy to access." **(Ann, former carer of both parents)**

"I AM IN FULL SUPPORT OF LOCAL GROUPS
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, Carer for her husband who has fronto-temporal dementia)**

- There seems to be an assumption that peer support groups can be facilitated by volunteers, current carers and/or former carers. This is a lot to expect, as maintaining well-functioning support groups requires skilled facilitation, long term commitment and follow up. Volunteers often volunteer their time to have their own needs met. Carers are often occupied with the demands of their own caring role. Former carers may have to attend to their own health needs as they age. Certainly carers, former carers and volunteers have a valuable role in assisting with running support groups, but they require training and supervision. Funding need to be allocated to this.
- Access to information is vital for carers. Many prefer face to face interaction to online, and many express the view that GPs need to know more about local carer support services.

**Here are some quotes from carers:**

"A carer needs all the information from the start, so they know what to do and where to go to get the information they need.
#. I wonder if GP's and Specialist are aware of what services are available in their area. Do they have phone numbers and pamphlets to give out. If they have a patient who is a carer and can

see they are having problems, they would be able to suggest to them to get in touch with their local support groups.
#. Carers need to be made aware that they can get Disability Parking permit for the person they are caring for. The permits make life easier if you have to take someone to appointments.
#. Older carers will have trouble filling out the questions for the ACAT assessment. It would be good if there were people available to fill out the forms.
#. 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. Unless the forms are made much simpler and easy to understand. An older person would be more comfortable sitting talking to someone face to face or chatting over the phone."
**(Ann, Former Carer to both parents who had dementia)**

"Here is my comment:
Page 17. Awareness and community linkages...Primary channels for this service will be.......G.P.'s ??? What only G.P.'s, not specialists as well.
I don't understand their thinking on this.

The day I became a carer was when my husband was diagnosed with dementia by a geriatric specialist. (My husband's G.P. did not think my husband had dementia, so I got a second opinion which resulted in a referral to the much needed testing and eventual diagnosis). I believe not all G.P.'s are dementia aware. This awareness is what we need nationally.

This geriatric specialist gave us information to attend a group, which we did, and haven't looked back. We were both unprepared for this diagnosis and have found wonderful help from these small community groups and Alzheimer's workshops.

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."
**(Beverley, carer for her husband who has fronto-temporal dementia)**

Comments on the draft Service Delivery Model for a proposed new carer support service system- Discussion Paper, by Helen Mabbutt, 9th December 2017

"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. The draft Service Delivery Model for a proposed new carer support service system raises two major concerns for me. These concerns are for better service delivery and service quality.

- 1. 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.

- 2. 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 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 service provision. Under a new service provider that confidence would have to be built again.”

## Responses to Discussion Paper Questions – Sutherland Shire Carer Support Service Inc.

**Q: If you were operating a regional hub, how would you undertake service mapping for your region? How would you ensure that you had captured a complete view of the available supports for carers in your region?**

**A**: Have to look at the full spectrum of services for carers of people with frailty due to age, dementia, disability, chronic illness and mental illness

Have to look at all the possible supports for carers, including emotional support, counselling, facilitated support groups, peer support groups, advocacy, respite, education and training, recreational programs, retreats

In order to support carers in an informed way, the Regional Hub needs to know the regional services available to people over 65 years through My Aged Care and the regional services to be available to people under 65 with any disability through the NDIS.

We would also know about general community supports which have a respite effect, e.g. Leisure Learning, social groups, clubs, computer classes, library services, council workshops and information sessions.

- We would contact:

ADHC, DSS, Carers NSW, (including Together Program directory - all local carer support groups in this program), all CHSP programs, Neighbour Aids, Interrelate, CCRCs, Aftercare FACES program, NSW Health Carer Program and NSW Health sponsored CALD and other carer support groups; Carer Gateway, My Aged Care; local Dementia Advisory Services; CatholicCare Dementia Carer Support and Counselling, 3Bridges Respite and Carer Support Service

- We rely on our Sector Development Officer Melinda Paterson and our local Council Community Development Workers to facilitate Aged Care and Disability Interagency meetings, where we network and share information with other local service providers and obtain a complete view of the available supports for carers, who provides them and who the key contact people are**.** **Interagencies are a key component of accurate service mapping and facilitation of them must continue to be funded for effective service provision to continue.**
- The Regional Hub needs to employ experienced staff with very good local service knowledge and/or very good networking skills. Regional Hubs cannot be insular organisations; they must have a co-operative ethos of sharing information and partnering with other local services. The Regional Hubs should have a dedicated Information Officer/Community Development Officer position to maintain links with local services and disseminate accurate service information to staff in the Hub and in local services.

**Q: How to measure outcomes for carers without it being too burdensome**

- Quick evaluation sheets circling responses at support groups
- Verbal feedback on outcomes is the most valuable
- What outcomes to measure? Reduced stress, ability to keep caring at home, coping ability, emotional stability, feeling connected and less isolated, learning skills and strategies for challenging situations, feeling more confident, being able to advocate for self and care recipient, improved physical and mental health. Taking regular breaks is an outcome. Using services for the first time (or more) is an outcome, delaying residential care for a month is an outcome. Delegating care to others is an outcome. Managing anger, being mindful, reducing BP, exercising more, eating better, sleeping better, taking up a hobby or interest, making friends with other carers, are all good outcomes for carers.

- When measuring outcomes, bear in mind that carers' lives are very stressful and difficult. They are living with complex, grief filled and often chaotic situations.
  Small gains are OK! Short-term gains are OK! Just feeling better and feeling understood is an important outcome!! It is unrealistic to expect programs to "Fix" carers so they go away and don't need anything ever again.

**Q: What would you view as the essential components of a future quality framework?**

**A: Essential components of a quality service**

-Accessible for all groups of carers
-Approachable, friendly, helpful, empathic and caring staff who "get" the carer experience and appreciate the complexities of the caring role
-Engendering trust
-Accurate information given
-non-intrusive, and only relevant, data collection
-Consistent, open response to concerns, complaints or compliments
-Prompt response times to phone calls, referrals, emails, requests for information
-High quality services, e.g. support group facilitation, advocacy, assisted referrals
-Consistent positive feedback from carers
-Training of staff in carer issues, groupwork, grief and loss, dementia and disability education

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