

**Carers and Disability Link Inc.**

**Submission**

**Delivering an integrated carer support service: A draft model for the delivery of carer support services**

Carers and Disability Link Inc. is a Carer Support and Disability Service Organisation operating under the South Australian Carer Support Model. Carers form the majority of our membership, as well as the majority of members on our Organisation-wide Board of Management and on our Regional Advisory Committees.

Carers and Disability Link Inc. broadly supports the guiding principles and proposed support elements outlined in the Integrated Carer Support paper and as a:

* member of the Carer Support Network SA;
* one of the original Carer Support Organisations in Australia that was developed and grown by Carers themselves; and
* an organisation that is still driven by Carers,

we submit the following feedback to the Department of Social Services in relation to this paper.

**Design**

The overall model does bring together the vital components of Carer Support, but it is in the delivery that that it will be determined whether it works or not, whether Carers in SA will be worse off under this model.

Based on the draft we still feel there will be a significant reduction in the amount of and quality of support available to Carers in SA. This design is that this is based on a service delivery model rather than a community support model. The value of local support and community connections/ownership will be lost in this model which raises the cost of Carer Support. There is no real capacity to support volunteers – increasing the cost of staffing the support. There is no real local focus which reduces the likelihood of community donating their time and money to this support. The model used by Carers and Disability Link is extremely cost effective due to the flat structure of the organisation, the use of volunteers and the funds raised by local communities. All these existing relationships and infrastructure will be lost in the new design making it more costly right from the start.

This model is moving more people into the service system than were there before. Carers require a community model to meet their needs, not a service driven model without connections at the level where they would naturally get the supports they need.

The benefit of what is done in SA is that we are empowering people to not become part of the service system, but supporting, equipping and skilling them to find their own ways to support themselves and each other.

This model, based on the assumption of Regional Hubs covering large regional area, will also see the loss of local infrastructure, and experience and knowledge already established to support carers in SA.

Consultation with Carers provided the following comments on the design:

* Carers reaction to the model is that the regional and local components should be the other way around (less at Regional and more at Local), and the National component be delivered at the regional level. They feel having 3 levels does not show an understanding of the urgency of carers needs.

There are too many phone symbols on the design overview: Carers gave many examples of the headaches of getting services via a telephone. They are vehemently opposed to any phone assessment or the need to phone someone at a call centre for support. Their experiences with Centrelink, NDIS, MAC, Families SA, etc. have shown them that they cannot present their case well over the phone, and the waiting time creates tension in the home as the care recipient gets impatient with them or suspicious of what they are doing. They like the local centres as they are face to face allowing for quick responses and far greater capacity to explain their situation.

They want the carer support centres to continue as they provide them with so much confidence in just knowing they are there and they can just drop in for a chat and a friendly face. They say they “save family relationships”.

* Carers felt that the new design would lead to loss of self esteem, loss of wellness and increased isolation based on the:
  + removal of the face to face opportunities they have at present (even just coming and saying hello to the reception staff was important to them),
  + removal of the relationship they have with support staff who have known them for a number of years and know how to advocate with them and relay information in a way they understand - because “sometimes we don’t know what we need, we only see the problem”,
  + loss of the uniquely individual support that they have received to date, and
  + less capacity to be self-directive in their support.

**Recommendation:**

* In SA the local carer support centres should continue as they are well placed to deliver any of the activities that the new model requires (just add more technology), they have the confidence of Carers themselves, and they have been established by carers themselves to deliver supports in the way that they want. They are already established and staffed and connected to carers and local communities, and there are only 5 organisations for Government to deal with. The cost to establish and then reconnect with carers and community would be far greater than the ongoing operation of these centres. It would be grossly detrimental to Carers in SA if they had to re-establish relationships with support workers just because the model is not flexible enough to allow them to have what they feel is right for them.
* The model in SA could be implemented with less regional hubs with most of the delivery of support activities undertaken at the local centre level. To make sure no Carer in SA is worse off it should be that SA tender is a variation of the other states and that it is a split of activities between Regional Hubs and existing local carer support centres based on current situation – eg. A regional hub could oversee the existing local carer support centres and provide higher level advocacy, research and links to Government in their regions, but have less activity at the regional level and more at the local. This takes the onus off Government to deal with smaller entities, the onus off regional hubs to re-establish carer support in SA, and Carers keep what they established.

**Regional Carer Hubs**

As well as what is noted above under design.

Although there is no indication of how many Regional Hubs there will be, we are fearful that this will be minimal in number (around CRCC numbers) and therefore remove the already established connections generated by the local support centres, staff and volunteers (inc. peer support). Not only will there be this loss of connection, there will also be a loss of expertise and knowledge from the sector. The added benefit of local support is the ability to respond to carers in crisis.

It is good to see short-term support to navigate, coordinate and access other services as this will be needed. This is a significant component of the support carers receive through the Carer Support Model in SA and means so much to Carers.

**Access to online/face to face services**

Balance is the key between online and face to face. It should never be forgotten that a lot of the carers are older, poorer and in locations where there is limited internet access.

As noted above, Carers report that they prefer the face to face contact and the opportunity to get to know the person they are looking to for support. Relationships have been the key to the success of the carer support model in SA and in satisfaction surveys this is what Carers rate most highly. Taking out that opportunity to meet face to face will reduce the number of Carers seeking help and in turn increase the number of care recipients or Carers themselves entering the more costly aged or health systems earlier.

**Branding and Awareness**

The key to raising awareness is not a national campaign, but connecting with people who are connecting with families. A good example is the close work done with schools that gets the message to young carers.

Assuming that other Government funded services will support delivery of awareness is not something we would have faith in at the moment with the issues around MAC, NDIS and even the RAS and the problems with how they work.

**Information and Advice**

Information and advice from other services focused on services to clients (not carers) does not work as well as getting that information from a skilled carer support provider.

A great example is decline in referrals for Carer Support since the introduction of MAC. In the past Carers heard about carer support available to them from other local providers as they chatted about their families needs – now there is no conversation, the Carer is being referred straight to MAC to start the ‘service’ journey for the person they are caring for and they are missing the local information about how they themselves can be supported.

Carer comment:

* the larger Government services are difficult to deal with, time consuming and impersonal (ie. don’t understand rural community living – can’t find us on a map).
* it saves time and stress using a local carer support person as they are the experts in using the existing systems, identifying what is available to solve their problems, and getting them the information they need.

**Peer Support**

The benefit of Peer Support Groups are many, and they provide a very cost-effective way of supporting carers. With this model our fear is that Regional Hubs can put peer support groups in places convenient to themselves and leave big swags of country without peer support as it is too hard and more costly.

The set up of peer support indicates that there would be a local provider to “establish and support the ongoing management of local peer support groups” which seems to indicate that there is the expectation that there will be local structures to do this or an assumption that local carer support structures will continue on and will do this.

Carer Retreats and Outings are valued highly by Carers because in themselves they include information sharing, peer support, informal counselling, respite, awareness, etc. Carers connecting with each other is what leads to creation of communities of acceptance that will continue even if we are not there, but someone needs to bring carers together and empower them to make this happen.

Carer Comment:

* repeatedly requested that the social activities and connections such as Carer Retreats and Outings be allowed to continue. They are extremely concerned that they will lose those social connections and be back to where they were before.

**Education and Training**

Again Carers are missing out when it comes down to other funded services delivering to Carers. The provision of education and training in the country has been a real fight in some areas and is non-existent in others, appearing to only happen at the convenience of the funded provider. There needs to be a way to ensure training is accessible (and accessible is based on Carer ability to get there) to all Carers no matter where they live. An example of how this will not work: NDIS have a funding stream ‘Training for Parent/Carers’ however they are not giving Carers access to these funds saying training is part of the Therapists role – therefore saying parent/carer education is only about the participant and how to work with them, not how to maintain a caring role. Carers are not the focus at all.

Education and Training also needs to be available to Carers as they need, as often as they need and in a format they can relate to – all of this because they are on a journey where there is constant change as the needs of the person they care for change. It is evident that this is best understood by people skilled in working with Carers, where as those not skilled in this area try to put restrictions and mandates on their education and training provision.

Face to face education is the best as it provides the added benefit of peer support as Carers meet each other and relationships develop. This then reduces the support needs of the Carer, as their natural supports are growing.

Local support to undertake Education and Training will be essential in gaining participants, transport (crucial in remote areas), and accessing suitable locations. Delivery by local staff with relationships with carers, means more carers are likely to attend as is proven over and over again with Dementia Training provided from outside the region – attendances are doubled when the local support personnel are involved.

Carer Comment:

* it is critical to have training and education within this model as it is not available in the other systems, even where it is promised (eg. Foster Care, NDIS)

**Counselling**

It is great to see provision of counselling at the local level to meet the different needs of Carers, especially those who prefer face to face. This needs to come in a range of support options from formal to informal and non-therapeutic counselling.

**Needs Assessment and Planning**

Good that this is a self-assessment. Need good local knowledge to assist Carers with their crisis plan. It is unclear who would do this as mentions both peer support facilitators and carer support staff from regional hubs. If it can be peer support facilitators then how do they access the resources to do this.

**Coaching and Mentoring**

This should not be compulsory as this is about Carer Choice and the benefit of the Carer Support Model is in the ability to adapt to Carer need and be flexible enough to make the difference that the Carer needs. If it is targeted and tailored then it should be that the Carer can say they don’t want it.

Also Carers are the experts in their own lives, and to assume they need/want a coach or mentor could be insulting.

**Short-term Respite**

Respite should be there to respond to crisis and to allow Carers to partake in activities that enhance their ability and capacity to continue in their caring role which may include opportunities for social connections, wellbeing and resilience activities, etc. It is important not to make respite a difficult thing to obtain and to make sure Carers are comfortable using it when they need it.

Accessing emergency and short term respite through existing community care relationships and infrastructure is questionable, particularly in more remote areas. The loss of care support centres in SA would also reduce the ability for these rural and remote carers to access respite as the CRCC’s are using these centres relationships, infrastructure and workers to deliver in these areas as they have no capacity themselves.

**Targeted Financial Support**

Finance and administrative staff need to be part of a team undertaking financial support and their FTE’s should be factored into this cost.

**Ensuring a sustainable and viable sector**

With our existing regional and local delivery of Carer Support, SA already has the capacity to implement this model with no disruption to Carers, no additional cost, and the opportunity to research its effectiveness immediately.

We suggest that the most sustainable and viable model is the one in South Australia which supports over 20,000 carers. To us the ideal is to continue this model with its additional value/benefit of community support, particularly in the country regions. The current design offering will not continue this community connection, risking the loss of a substantial amount of support for SA Carers. Support to Carers in SA is not extravagant or wasteful, it is cost effective, brings in substantial community support, and can operate under a flat management structure that keeps staffing costs down.

If we cannot retain our model, then we would like a guarantee that SA Carers are no worse off under any changes to Carer Support Funding.

For Carers and Disability Link, our community would like to know how they can continue to support their local carers under this new structure. Our Board, Advisory Committees, and Fundraising Groups do not want their community raised funds to go outside their communities or to see the Carer Support Centres they raised funds to establish not be fully utilised.

**Discussion Questions:**

**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?**

We are concerned by the focus on services and some of the mechanisms for achieving these outcomes. The objectives and mechanisms make this model a service provision model, rather than a support model, which will lead to greater service dependency than currently seen under the Carer Support Model in SA. An objective about empowering people is needed - supporting, equipping and skilling them to find their own way of supporting themselves and each others (communities looking after themselves).

**In regards to the specific objectives:**

“To encourage and normalise uptake of services…”, ignores the best way to support carers – through community connections, which is far most cost effective and beneficial to everyone in the long run. Yes, there are services required, but this design will not reduce this over time, it will increase service dependency. In SA we are getting great outcomes for Carers and reducing service dependency through a focus on community support and connections rather than service provision.

“Help more carers” is a great objective and adding other channels for service delivery is a good move. Yes, as noted in the productivity report we do need to maximise the how much money goes toward carer support which was not happening under the CCRC model. But when there is an efficient model out there, then that should be maintained rather than thrown out with everything else.

“Deliver a service carers will value” means that carers need to trust the provider and this is based on developing a relationship with the carer. Research shows that this cannot be done at a distance, so to meet this objective the model needs greater focus on local and face to face. If we miss the relational in this model, what we will end up with is a patchwork of much needed support underneath the Integrated Carer Support Model that is then funded by local communities (where they can), or more likely funded by other small, short-term grants that in the end the Government still pays for in some way.

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

On-line counselling has not seen a good uptake by Carers of any age, so the inclusion of accessible face to face counselling will be critical.

The loss of local carer centres, will mean loss of the community connection that this brings, loss of opportunities for volunteers and community ownership, loss of opportunity for communities to give to others, and loss of capital raised by the local community. All leading to reduced opportunity for carers to create their own community, and/or feel supported enough by their community to utilise those natural supports. Also, the loss of the most cost effective way of supporting Carers due to loss of volunteer base, community support (venue access, transport, donations, etc.) and fundraising.

This will have the biggest impact in rural SA where the carer support organisations are a part of the local community. They not only connect carers to the local community, but provide a community hub at the same time (reducing the need to use other Government funded services as well).

We would like this model retained in rural SA as the demise of this would have such a huge impact not only on registered Carers, but on the communities including those hidden Carers.

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

To get a true picture of the support available at a local level you need to move in those circles as just looking for “services” will mean you miss the other supports that local people know to connect in with, such as community groups, volunteer groups or support through activities not in the aged, disability or mental health space that could help an individual. To do this you also need to ensure you are finding out the individual needs of each Carer – it cannot be a one fix for all.

Having a local person on the ground, being a part of the local network meetings, contributing to these so people supporting others in the community feel they can trust you as part of their community and as someone they should share with.

**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 carers 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 outcome should be focussed on the Carer continuing in their caring role, with support to get the resilience they need and the ongoing support they need from within their natural communities (either existing communities or ones they have created with others they have met on their caring journey).

Carers felt that outcomes could be measured by surveys at groups, looking at wellbeing, if coping , have confidence, in-control, physical health…. A question they felt would say it all was “How would you feel if this support suddenly disappeared?” Also a questionnaire at the start and at regular intervals would be another way to show a difference in how they felt and how they are coping now. The outcome they want is that they are coping and in good health (mental, emotional and physical).

**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?**

One that already exists, so that there is not another framework for providers to comply with, that will take away valuable staff time or lead to greater costs with another administrative/management staff member required.

The biggest consumer of staff time, aside for working with carers and clients, is accountability requirements. These are now so big and bring up so many obstacles (portals that change, go down, don’t work, don’t talk to your systems, have call-centres where the wait can be up to an hour, have updates that change what you put in, etc.) that they are eating into time everyone would rather spend with carers and clients – this is not fair on them.

Carers say that the bottom line for them is that they are coping, confident, in control and in good health – if that is how they judge quality outcomes and we can say we are doing that for them, then that should be what we are judged on and then we can move on to help someone else as well.

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