



## **Submission regarding “Integrated Carer Support Service”**

Community Lifestyle Accommodation Ltd (CLA) welcomes the opportunity to submit this paper to the Department of Social Services in relation to the recently released consultation paper “Delivering an integrated carer support service – a draft model for the delivery of carer support services”.

CLA is a grassroots, community-based organisation that has risen to respond to the needs of ageing carers, and their middle-aged sons and daughters with disability. CLA supports 45 carers who are aged between 65 and 88 years on the Mornington Peninsula in Victoria. It does not receive any government funding support for the work it does. These carers are in urgent need of proactive and flexible support that will enable them to continue in their caring roles.

CLA provided a response to the consultation paper “Designing the New Integrated Carer Support Service” released in May 2016. We have attached this response again as background to this current submission to prevent duplication and to reinforce the points made in that original document that remain both valid and of high priority to carers in the Mornington Peninsula area of Victoria.

We note that the new consultation document makes welcome statements about the key strategic intent of this approach to carer support.

- We strongly support the statement on Page 30 “Therefore, a good service experience is critical to ensure that carers will want to access the service. If carers were required to speak with a centralized contact centre prior to accessing support, they may view this as a barrier”.
- It also says that “Carers have told us as part of our research that they want to talk to a skilled and knowledgeable person with whom they can build a relationship, and not have to repeat their story.”
- An additional constructive point made through out the document is that carers need to be supported early in their role as a carer, through effective supports that they are confident in approaching as and when they are in need of that support.

Given these strong and relevant points about the intent of the service, it is disappointing to read the design of the proposed model and how it might operate at national, regional and local levels. The model appears to be built around achieving the lowest cost ‘service’, a service that is too heavily oriented toward on-line and technology based support and poorly defined regional hubs that will fail to offer genuinely local support and solutions.

We would like to make the following points in relation to the model as it is currently designed in the hope and expectation that these concerns will be understood and acted upon.

- While it is true that technology is increasingly being used by many in our community, including carers, this does not mean that the optimal solution is predicated on developing a service that relies so heavily on technology solutions. Much of the proposed information is already available on line for those who prefer information in this format but for many, reading vast amounts of information, that may or may not be relevant, to find the right solution is time intensive and often unsatisfactory. On-line forums and support groups have limited value, particularly for ageing carers. Carers have said that they like face-to-face arrangements and supports. Carers really need a personalised, local

response that is tailored to their unique needs. Technological responses cannot offer such tailored support; can be affected by virus, worms and hacking; and requires significant resources to keep data up to date and relevant. It seems that a cheaper solution will not necessarily result in a good financial return.

- On-line self-assessment and establishment of accounts is intimidating to many, and for others, an intrusion into their privacy. Many older carers will probably disengage from the service as soon as this is suggested.
- Many, if not all of the services, appear to require contact through the national number, rather than through the regional hub or localized services. This is an extra step that may well prove to be a barrier to individuals progressing to take advantage of other service offerings.
- While the goal to achieve earlier contact and support is laudable, and indeed necessary, this model does not appear to have any genuine outreach capacity and therefore remains a passive approach to carer identification and support. This will not effectively shift the system from crisis response to proactive early intervention and support. Carers first come to the attention of General Practitioners, maternal and community health services, early intervention services, hospitals and schools. There appears to be no proactive attempt to engage with these, and other front line, services for early identification of carers, active referrals and early response.
- Once a new carer is identified, it is helpful, with their permission, to establish an initial, helpful but empathetic relationship. True, carers do not want to repeat their story over and over and the best solution for this is to ensure that carers have a clearly identified individual supporter who is local and engaged, knowledgeable and available. Relationships cannot always be established successfully over the phone or internet. It needs an offer of personal connection, face-to-face, and preferably in the family home contact where the real situation is more easily assessed and the beginning of an informed partnership can begin. This will assist the essential positive first contact that will encourage carers to continue to use the service. As we said in our previous submission "Research has demonstrated that proactive engagement with a 'support coordinator' has significant value in reducing crisis, deterioration of relationships and cost of interventions. Instead, separate support components of intake, planning and mentoring have been identified in the report without a clear approach to integration of these roles and responsibilities. In reality, these are parts of the same role, a supportive role that develops relationship, partnership and trust leading to proactive and personalised response. This connection to a carer, maintained over time and contact, provides both proactive and reactive support as needs or circumstances change".
- The regional hubs have not been identified as they are still under consideration by DSS. This means that they could in fact be large areas supported inadequately by staff who will be challenged to maintain an effective working knowledge of local needs and options.
- Funding arrangements for peer support groups appears to be through the regional hub but there is a significant lack of clarity around whether specific funding will be made available for this purpose, what will be funded and how local the response might be.

- Local service funding appears to be entirely lacking thus presenting the assumption that currently funded service providers will meet local needs. There are two flaws with this assumption. Firstly, local services are not currently meeting local needs for proactive, holistic supports wither due to capacity or knowledge. Secondly, local services have an inherent conflict of interest that may mean that they recommend only their own services. It is disappointing that this issue has not been adequately considered or addressed.
- Research has demonstrated that proactive engagement with a 'support coordinator' has significant value in reducing crisis, deterioration of relationships and cost of interventions. Instead, separate support components of intake, planning and mentoring have been identified in the report without a clear approach to integration of these roles and responsibilities. In reality, these are parts of the same role, a supportive role that develops relationship, partnership and trust leading to proactive and personalised response. This connection to a carer, maintained over time and contact, provides both proactive and reactive support as needs or circumstances change.

We are aware of the many supports available for people affected by mental health concerns, disability and ageing but if government really wants to make a cost-effective difference in the lives of carers, they would establish a localized carer support service that proactively invests in individual carer engagement, regular supportive contact and connection to neighbourhood supports. The benefit of excellent planning has been proven in disability and aged care services. It is hoped that adoption of such a system, backed up by appropriate access to flexible financial resources, will be achieved for carers, thus enabling them to be in the 'driver's seat' of managing their own arrangements. What we are advocating for is an investment in upfront supports that will significantly increase carer capacity and resilience while providing a timely response. 'Front-loading' investment in carers will reduce dependence and costs in the longer-term.

Government commitment to ensuring effective and flexible support for carers makes good practical, social and economic sense. We hope that the final configuration of the framework will demonstrate how effectively government has listened to the myriad needs of all carers and will ultimately design a framework defined by its genuine responsiveness.

Marie Hell

[marie.hell@bigpond.com](mailto:marie.hell@bigpond.com)

## **Submission regarding “Designing the New Integrated Carer Support Service”**

Community Lifestyle Accommodation Ltd (CLA) welcomes the opportunity to submit this paper to the Department of Social Services in relation to the consultation paper “Designing the New Integrated Carer Support Service” released in May 2016.

CLA is a grassroots, community-based organisation that has risen to respond to the needs of ageing carers, and their middle-aged sons and daughters with disability. CLA supports 45 carers who are aged between 65 and 88 years on the Mornington Peninsula in Victoria. It does not receive any government funding support for the work it does. These carers are in urgent need of proactive and flexible support that will enable them to continue in their caring roles.

The consultation paper demonstrates the challenges and complexities of providing effective carer supports in an environment of change and resource constraints. It is in the interests of all stakeholders to understand and respond to the challenge of ensuring effective, flexible and timely carer supports.

The paper discusses the wide range of supports that are currently available, research about the efficacy of those supports and the views of three major stakeholder groups. The proposed ‘Integrated Carer Support Service’ would appear to offer a comprehensive range of potential supports but the approach to coordination, delivery and administration of those supports appears unclear.

In general terms, CLA would like to make the following overarching comments:

- We welcome the expressed focus on meeting the unique needs of each carer.
- The emphasis on identifying carers who are not currently known to, or engaged with, the current system is extremely positive.
- The proposal to provide employment and support services to individuals who will no longer have a caring role is a constructive initiative.
- The benefit of excellent planning has been proven in disability and aged care services. It is hoped that adoption of such a system for carers, backed up by appropriate access to flexible financial resources, will be achieved for carers, thus enabling them to be in the ‘driver’s seat’ of managing their own arrangements.
- A local response is identified but can mean many different things to readers. It is essential that a genuinely local response is assured through the maintenance and further development of services that are in close proximity to those that need those supports. No carer, except in the most remote areas, should need to travel more than one hour to obtain support as the burden of travel can defeat the intent of the intervention.
- The paper has not fully captured the experience that many carers have had in connecting with important information and receiving adequate support. Carers often feel let down by larger organisations that do not appear to be in touch with the grass root carer needs. There is a real need to ensure capacity for face-to-face contact, particularly through home visits, as a first step in establishing relationship and rapport that in turn can lead to urgently needed friendship, support and engagement with the community.

- Many carers do not have access to the internet and there appears to be an over-reliance on this medium of information delivery.
- We are concerned about the continuing focus on targeting supports to those most in need. This would appear to be a continued focus on resource rationing that implies continued investment in 'gatekeeping' and crisis intervention, rather than proactive support delivery. As additional carers are identified, demand will grow. If the system then excludes or doesn't prioritise a particular carer's needs, that person will become disappointed or disengaged and potentially fail to receive the supports they need. Significantly, if increasing need is not identified or addressed in a timely way, the cost of response will be far greater than it need be and the impact on the caring relationship could be devastating.
- Research has demonstrated that proactive engagement with a 'support coordinator' has significant value in reducing crisis, deterioration of relationships and cost of interventions. Instead, separate support components of intake, planning and mentoring have been identified in the report without a clear approach to integration of these roles and responsibilities. In reality, these are parts of the same role, a supportive role that develops relationship, partnership and trust leading to proactive and personalised response. This connection to a carer, maintained over time and contact, provides both proactive and reactive support as needs or circumstances change.

In particular, CLA would like to comment on the need to further develop meaningful peer support programs. It is our belief that these programs are best run through regional or sub-regional carer networks that are run by grass roots carers supported by a funded and suitably qualified staff member. This structure ensures that carer networks and peer support arrangements can flexibly and relevantly respond to the needs of carers in the local area. Peer Support would promote connection between carers and relationship-building to reduce isolation, as well as being a source of essential information. While separate from the formal system, and managed through Carer Committees, there would be a symbiotic relationship with other Carer organisations and with the formal system. With strong connections to formal carer support programs, cross-referrals can ensure responsiveness without the need for complex eligibility assessment criteria at that peer support level. In turn, this lack of formalization of assessment will attract individuals who do not wish to become engaged in the formal service system. Instead, they will have the support and assistance they need and want at that point in time. As their needs or circumstances change, streamlined access to formal support arrangements can be anticipated and facilitated.

The Peer Support Worker would provide low level support to carers by facilitating carer support meetings; ensuring access to a wide range of information on formal supports; developing and maintaining informal contact with carers through phone calls and home visits; and assisting with advocacy at the request of the carer. With regular contact, the Peer Support Worker will be able to understand changes in a carer's capacity to continue to cope and whether resilience is diminishing. This is crucial if early intervention is to be achieved in the best interests of the carer and the cared-for. It is intended that the Peer Support Worker would be suitably qualified and that he or she would receive effective support from the local Carer's Committee. This support would be augmented through participation in Peer Support Worker networks and connections with formal carer support services.

In effect, the Peer Support Program would form the first and most accessible tier of a two-tiered response. The second tier would focus on carers in need of formalized supports as identified in the Service Concept.

Government commitment to ensuring effective and flexible support for carers makes good practical, social and economic sense. The final configuration of the framework will determine its effectiveness and viability.

Marie Hell  
marie.hell@bigpond.com