



Submission: Developing of a Victorian “Carer Statement”

Community Lifestyle Accommodation Ltd (CLA) welcomes the opportunity to submit this paper to the Victorian Government via Carers Victoria in relation to “Developing a Victorian Carer Statement.

CLA is a grassroots, community-based organization that has risen to respond to the needs of ageing carers, and their middle-aged sons and daughters with disability. CLA supports older caring families who are aged between 60 and 90 years and also is growing to meet the needs of younger families who are in urgent need of support 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.

In general terms, CLA would like to make the following overarching comments about what carers say they need and want in our everyday interactions with them:

- We welcome the expressed focus on understanding and responding to the needs of carers and the recognition of the immensely important role that carers play.
- We emphasize the need to recognize that many carers are not currently known to, or engaged with, the current system and that effective outreach is needed to identify and either engage or re-engage with these individuals who often feel forgotten and ignored.
- 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 required. 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.
- Carers often find it difficult to obtain the information that they require. Carers often feel let down by larger organizations 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 older carers do not have access to the internet and there appears to be an over-reliance on this medium for information delivery.
- In the past, there has been a tremendous focus within government run and funded services on rationing scarce resources. Therefore, attention was primarily focused on those most in need or at the point of crisis, rather than a proactive, positive approach to early information and support. If the system excludes or doesn’t prioritize 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. Integration of intake, planning and support roles within a single, seamless support coordination response is logical and responsive, enabling a relationship of understanding and trust to develop, leading to proactive and personalized response. This connection to a carer, maintained over time and contact, provides both proactive and reactive support as needs or circumstances change.

CLA coordinated a forum in Hastings to provide input by carers directly into this project, Carers Victoria facilitated the session. We would like to take this opportunity to reiterate what carers said is important to them.

- Carers raised their concerns in relation to their rights. They expressed their valid concern that carers do not have rights to a break under the NDIS as the total focus is on the person with the disability, rather than those who have, and are expected to continue to sustain, that person. In effect, carers feel that they are often exploited and should be grateful for the small amounts of support they are offered.
- The NDIS planning process often fails to take account of the carer's role in providing a voice to the person with a disability especially those with a severe / profound intellectual disability. In reality, poor planning means that ageing parents are bearing the brunt of poorly conceived individual plans and this cannot be allowed to continue.
- There should be a lifestyle of choice for carers –a regular life, parent-worker-grandparent -member of the community.
- Carers often marvel at the reality that they are expected to manage alone but support agencies feel the need to send two staff members at once to meet the support needs of the person.
- Respite is getting harder and harder to access as there is inadequate facility-based respite, particularly as individuals in crisis take up scarce beds on a more or less continuous basis until a solution can be found. Carers say that they need affordable choices of respite including recreational options particularly for high support individuals.
- There are significant gaps in the service system. These include, but are not limited to supports that are available after hours and on weekends/public holidays, and supports available during school and day placement holidays. This puts very significant pressure on families and carers. It also affects a family's financial position substantially as carers need to reduce work to meet their son/daughter's requirements.
- Transport is a major issue for older carers in their 70's - 80's -90's whose sons and daughters rely on parents to access the community. NDIS allocation of \$2,472 for the person to attend day service, outings etc does not consider the older carer. Perhaps the State could consider funding for this target group.
- There is a genuine and urgent need for suitable housing options. The lack of these options adds stress in relation to longer-term planning for carers especially older carers. Many fear that a solution will not be found by the time they are too ill to continue their role. Housing choices need to be made available in appropriate locations and with a variety of unit sizes in small developments so that the prospect of social isolation is reduced.
- Carers do not stop being carers when a person is supported to move to a new home with supports. To ensure good quality of support, and the reassurance for carers that comes with this, the following are seen to be important:
 - A person and their carer need to be supported through a well-planned, individualized and responsive transition. This enables a trusting partnership to form in the best interests of the person.

- Staff need to be person-centred, empathetic and competent. They must be respectful and supportive of the carer's role in the person's life.
- Abuse /neglect to people in care must be addressed immediately. Vulnerable people need to be protected.
- Most of all, carers have said that they want local support through an advocate or caseworker who is locally-based, can assist with meaningful information and who can reduce the barriers to gaining support/service access that can make a carer feel it isn't even worth it to try and get a meaningful support. They want an effective advocate and a user-friendly system that alleviates rather than increases pressure on carers.

In particular, CLA would like to comment on the need to further develop independent meaningful, local carer 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 carer support arrangements can flexibly and relevantly respond to the needs of carers in the local area. Local Carer Support would promote connection between carers 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 organizations 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 carer 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 Carer 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 Carer 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 Carer 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 Carer Support Worker networks and connections with formal carer support services. Community organizations could be enlisted to play their part in supporting caring families to stay connected to their communities.

In effect, the Carer 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. We understand that the Carer Statement is just a first step but it is important to highlight the urgency of a genuinely responsive local support network for carers. In the end, a 'Statement' is just words on paper, what we urgently really need is (community building) funding at a regional level and support to achieve an effective, efficient investment in local carer advocacy and support.

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