Victorian Carer Services Network

VCSN Carer Blueprint

Achieving Sustainable Caring

Executive Summary

The VCSN recognises that the current suite of community sector reforms provides an opportunity to enhance carer support in a holistic and consumer focussed manner. This paper, developed as a response to input from over one hundred VCSN members, during the 2015 VCSN Learnings from Practice Forum, discusses what is working for carers, what is not working and the opportunities that exist to enable and develop sustainable caring.

The evidence from our clients is that they are being supported in their caring role through:

- their existing natural supports,
- the provision of flexible, tailored services,
- the availability of 24-hour, short-term or immediate respite,
- the increased recognition within the community of their caring role,
- the availability of skilled and experienced support staff, and
- government's commitment to supporting the care relationship.

Our clients tell us that their capacity to fulfil and continue their caring role is constrained by:

- The increasing financial burden associated with caring, especially income loss,
- The physical and emotional impact on their own health and wellbeing,
- The social isolation they experience,
- The inconsistency of quality services across the State, and
- The failure of service providers such as health care agencies to recognise their role in supporting the wellbeing of the care recipient.

The VCSN believes that the current raft of systems reforms provides an opportunity to move away from a reactive approach to an early intervention framework that engages carers in all phases of their caring role and to create a service system that provides efficient referral pathways and effective interventions for carers.

VCSN recommends that any future carer support framework should be supported with nationally consistent tools and:

1. Retain unique, dedicated, well-resourced support functionality for carers across the aged, mental health and disability sectors. This should recognise the unique needs of carers as a cohort and be augmented by a sector capable of providing accurate and current information regarding access, support and applicable allowances as well as specialist carer support.
2. Focus on flexible and responsive support for carers, recognising that respite is a relatively minor but important component. This should be further supported by distinguishing brokerage from support functionalities.
3. Retain a focus on carer wellbeing to support sustainable caring, recognising the pivotal role carers play on an individual and collective basis.
4. Enhance support service access, irrespective of geographical constraints. We recognise that this is resource dependent, but advocate that an early intervention approach reduces resource utilisation in the long term.
5. Focus on carer sustainability in all support activities, recognising that at best, the service system can only ever hope to augment and support carers in their role, and that this should always be done in consultation with carers.
6. Recognise that many carers support multiple care recipients and will require a range of supports at different times.
7. Be transparent and accountable by consulting with carers about the reform agendas and consequent changes to service systems.
8. Include a focus on carer choice as the foundation of all carer support systems and strategies.
9. Retain and enhance focus on promotion of carer recognition to create inclusive service systems and ensure that carer contributions are adequately recognised.
10. Recognise that in many instances, consumer directed care is best achieved in partnership with the primary, and even secondary carer, and ensure that planning and service delivery acknowledges and reflects this.

Introduction:

“Any one, any time, can be a carer”.

Carers Australia coined this slogan to summarise its Carers Week message in 2011. It signifies the universality of caring: caring may impact on people from all walks of life, at any time, for any reason. It may be time limited or ongoing. Caring is an extension of the carer’s life, and often requires unexpected adjustments to that life. All carers respond to the caring role uniquely, bringing differing levels of caring expertise and resilience. The Victorian Carer Services Network (VCSN) has over seventeen years of experience in working with and supporting carers. The Network was formed at the inception of the carer programmes in 1998, to ensure consistent approaches to carer service delivery across Victoria. At the time, carers told us of the need for dedicated carer services that could address caring issues separate from the care recipient concerns; this has formed the foundation stone for all of our service delivery, advocacy and representation since.

We know that, as family members or friends, most carers are able to provide the care that their care recipients need most of the time; our experience shows that caring comes at a premium. The current agendas of reform at a federal government level endeavour to streamline support for recipients Whilst we recognise that the aim of streamlining\e supports for care recipients is likely to have a positive impact on many carers, we are nevertheless concerned that the mechanisms under current consideration may not address issues specific to carers and the caring relationship, such as social isolation, compromised health, feeling overwhelmed, disempowerment and financial hardship, to identify just a few.

We believe it imperative to retain a formal capacity to support carers in their own right and not as an extension of the care-recipient. This applies to existing carers and those who will become carers in the future. We expect carer numbers to increase as the population increases, and in response to rising rates of dementia, enhanced medical technology and the trend towards care in the community / at home.

This paper discusses what is working for carers, what is not working and the opportunities that exist to enable and develop sustainable caring, and seeks to support VCSN members to advocate for sustainable future caring contexts. It is the work of over one hundred VCSN members who participated in the Carer Blueprint Workshop at the VCSN Learnings from Practice Forum in November, 2015.

What is working for Carers?

Formal systems support natural supports to strengthen sustainable caring:

In the current climate, there is a lot of uncertainty about the future of service provision. For many, the one thing that remains certain is access to their natural supports. For some carers this may come in the form of loving support of family and friends. For others an emerging and growing source of support is peer support, where even the most isolated carers may have the opportunity connect to peers through social media and facilitated peer support activities. These varied informal supports often enhance carers’ sense of resilience. Carers may experience additional benefit as they are provided with the opportunity to empower and be empowered through sharing knowledge about what works. This acquired knowledge and knowing that they are not alone and that someone will listen to them often increases a carer’s choice and sense of hope. This is supported by the findings of KPMG (2015) who found that Carers and consumers value the information and support services. Particularly where these services are delivered in a face-to-face mode.

Flexible, tailored service responses - access to service that specifically support carers:
Currently, there is a broad range of services offering support to carers across many domains, and carers have choice when seeking support. Locally, carers have access to the Commonwealth Respite and Carelink Centres (CRCC) and peak carers associations, and most recently the Carer Gateway. CRCCs offer a range of supports valued by carers. These include facilitated access to a range of emotional supports to enhance carer wellbeing; service navigation; access to social supports and advocacy. These are frequently delivered face-to-face, which is valued by many carers, who also appreciate just having someone to listen to them.

Respite:
CRCCs are also able to offer respite. Carers indicate that respite support is significant and access to 24-hour, short term or immediate assistance is valued by many who find themselves in need of urgent respite. However, for maximum benefit it is essential that planned respite is available. Respite should be offered with appropriate and agreed supports which are flexible and tailored to ensure the health and wellbeing of individual carers is met.

Recognition:
Carer’s report they have noticed increasing recognition of the vital role of they play and the value of the care they provide in the community. A significant strategy has been the implementation of Carer Recognition Act. This Act and its state counterpart focus on the broader needs of carers, and has played a significant role in enhancing systemic approaches to carer support. For example, carer leave is enshrined in most Employment Awards and Enterprise Bargaining Agreements, and carers’ rights to flexible employment conditions where possible are increasingly recognized. Australian governments remain focused on providing carers with access to the supports they need that will assist to build capacity and sustain their caring role. These include:

- Facilitated access to emotional supports
- Social support – connection with other carers
- Education & training - empowering and capacity building
- Service navigation
- Advocacy
- Carer support groups
- Peer support
- Targeted response to diverse community, with local knowledge
- Peer workforce

Skilled and experienced support staff:
Streamlined, efficient carer support relies upon specialist skills and experience. Carers appreciate that support services employ staff with requisite expertise, and ensure staff skills remain current. The commitment to a skilled and specialised workforce is an important feature of the current service design.

Commitment to supporting care relationships:
The Government's commitment to supporting care relationships is evident though various reforms. The recent implementation of the Commonwealth Home Support Program: Carer Support and Carer Relationship sub program restricts eligibility to clients who have a carer. Similarly, within the NDIS there are provisions for carers rights to support as Part 2, Section 31, (d) and(da) of the Act outlines that NDIS plans should:

> *".. where possible strengthen and build capacity of families and carers to support participants who are children" and for adult participants "if the participant and the participant's carers agree – strengthen and build the capacity of the families and carers to support the participant in adult life."*
> (http://www.carersaustralia.com.au/storage/carrrs-australia-submission-ndis-act-review.pdf)

The VCSN recognises the significance of the CHSP in supporting carers, and the government's commitment to carers. However, not all care recipients are eligible for the CHSP, and the program itself supports clients, not carers. As previously discussed, carers must manage their own response to their caring role and the circumstances surrounding it. Each carer's emotional response is unique. Resilience and resourcefulness will vary from carer to carer, and at different points in their journey. The ability to care may also be impacted by other roles that individuals invariably assume: professional, parent, spouse, child, sibling or volunteer. Supporting the care recipient does not necessarily entail carers will be supported in managing their caring role.

Summary of what is working well:
In summary, carers identify that the specialised, individualised, flexible responses that focus on individual carer well-being, provided by dedicated, skilled, experienced and well connected support services is what is working. CRCC staff report that the most common support request is for help in navigating the system. The following quote from a carer demonstrates the importance of skilled experienced and well connected support service:

"When you meet someone in the system who really understands -that is golden." (Carers Victoria, 2015)

What is NOT working for carers?

Obstacles to informal / natural supports that impede sustainable caring roles:

As previously noted, very few carers operate in total isolation. Most caring roles occur in an individualised context of natural supports. However, there are many obstacles to sustainable caring and many reasons for families and friends to ultimately reject the caring role.

Financial Burden:
One of the major obstacles to sustainable caring is the increasing financial burden faced by family carers. Many aspects of the caring role increase financial burden – travel to and from frequent medical appointments, equipment to enhance the recipient's wellbeing, cost of activities to support the recipient, etc. This is exacerbated for the significant number of carers who are forced to give up part or all of their employment to support a recipient. Government entitlements do not adequately compensate for either the increased costs of

caring or the reduction in salary. It is also important to note that many any carers are not aware of entitlements which exist and are often confused about their eligibility.

The significance of financial burden for carers has been quantified in a recently commissioned Carers Australia publication, which notes that full time employment rates for carers ages 20 – 54 are 20 – 36% lower than for the general population, and part time employment is 10-35% higher (Deloitte Access Economics Report, 2015).

In 2012, 38.4% of primary carers were employed, compared with the population average of 64%. (Australian Bureau of Statistics, 2013)

Carer Health and Wellbeing:

Due to the constancy of the caring role, and the physical / emotional burdens placed on carers who are supporting loved ones at home, many carers suffer from anxiety and depression; carers burn out and have higher rates of morbidity than the general community. The National Ageing Research Institute is currently undertaking research into carers wellbeing based on a broadly recognised understanding that:

*"Most older people with disabilities live in the community with support from informal carers. Carers are generally willing to take on the caring role but it often has an adverse impact on their physical and emotional health, particularly their mood and level of depression. There is evidence that the lower the care recipient's function, the more their carer may experience these problems. Currently we do not know how best to support carers and care recipients living in the community." (*National Ageing Research Institute, No date).

Carer Isolation:

The impact of isolation on an individual and in the community is well researched and documented. For instance, research undertaken by the Australian Institute of Family Studies and FaHCSIA found that "carers are more likely than the general population to have little face-to-face contact with friends or relatives outside the household, especially when caring for someone with high level care needs" (Edwards, B., Higgins, D.J. & Zmijewski, N 2007). The amount of time required to care for someone with high or low needs is a significant trigger for carers to become socially isolated. A consequence of this isolation can be a carer's inability to look after their own needs adequately. Over time, social isolation and the constant requirement to put another person's needs first can lead to carer burnout and ultimately leads to an unsustainable caring role.

https://www.carersnsw.org.au/Assets/Files/Facts%20about%20carers_updated%20April%202013.pdf

Inconsistent service access:

Despite significant efforts by service providers and government alike, there are inconsistencies in service access across the state. Brokered and support services may be provided by government funded agencies such as Home and Community Care. However, the majority of service provision is provided by small to medium businesses, which must meet business KPIs, and can only continue to operate if there is sufficient demand to maintain a sustainable business. This leads to inherent inconsistency in provision across the state, particularly in remote and rural areas, imposing additional challenges for carers trying to access supports.

Currently, the large majority of carers are elderly, with lower rates of computer literacy than the general community. As sector resources increasingly move online, many of these carers as well as those from CALD backgrounds or who are Aboriginal or Torres Strait Islander peoples are likely to feel further disenfranchised and disadvantaged because of the difficulty in accessing online supports, a lack of knowledge about and confidence to engage with online resources. This further impacts on access to services.

Lack of recognition:

We noted above that carers acknowledge an increasing community and government awareness about their role in the economic and social fabric of our society. However, recognition of carers has not necessarily led to real and profound changes in their lives which create further barriers to sustainable caring. Not only are carers inadequately compensated financially for the hours of care they provide, their place in the community is ambivalently understood. For instance, carers regularly report that they are made to feel "guilty" by their peers for accepting carer allowances and pensions. Healthcare organisations are notorious for ignoring the role and needs of the carer when prescribing medicine and after care regimens for care recipients and carers alike. We also note the growing trend within the community sector to just consider the recipient, evident in the eligibility specifically denying Home Care Packages and Commonwealth Home Support Program to people with carers. As discussed previously, there is an assumption that if the care recipient is supported, then it follows that the carer is automatically supported too, but this is frequently not the case.

Service sector obstacles that impede sustainable caring roles:

Impact of policy change:

As both State & Federal policies change at an increasingly rapid rate, so does the uncertainty within the service sector. With major reforms occurring in disability, aged care and mental health service provision, funding to carer programs is being steadily reduced, limiting both the operational capacity and brokerage available to support individual carers. Not only is brokerage decreasing, but the flexibility of carer programs is increasingly limited to 'traditional' forms of respite, such as residential or in home care. These factors compound the lack of clarity and clear direction around policy decisions and funding periods from all levels of Government. These factors are leaving many carers and service providers confused and unable to meet their needs, resulting in increased carer stress and vulnerability. Also, as service delivery is increasingly aimed at supporting recipients, carer concerns are too often ignored. In many instances, the importance of their roles is not understood and their needs are not supported.

Inadequate resourcing:

The service sector is inadequately resourced to have the capacity to support the needs of individuals with low or high support needs. Brokered respite funding is limited and highly proscribed. Appropriate services may not be available for purchase. The reforms to package levels and availability have the capacity to support more recipients. However, there can be lengthy waiting times between approval for and access to a package. Likewise, there is often a time lag between re-assessment for a higher level package and appropriate availability. In all locations across the state, there may be a limited choice of providers for specific conditions, with limited or inexperienced staff available to cover recipient needs, particularly where complex or challenging behavioural support is required. For individuals from non-mainstream communities such as Aboriginal and Torres Strait Islander peoples, members of the lesbian, gay, transgender and queer community and people from culturally and linguistically diverse backgrounds, the importance of accessing culturally appropriate and 'safe' spaces is high. However, limited funding to interpreters and culturally appropriate support in many regions across the state further reduces access and support. Lack of supports for recipients increases carer burden, and may impact adversely on carer wellbeing, particularly if carers have fewer opportunities to access respite for themselves. Care agencies may also to struggle recruit and maintain appropriately trained and credentialed staff, and frequently have high turnover of staff delivering direct care, resulting in a lack of consistency of care and the carer needing to re-tell their story numerous times.

System / Sector changes:

Whilst generally perceived as a benefit, the introduction of online websites such as My Aged Care and the Carer Gateway may ultimately reduce support to carers in their role. Some carers have reported that they feel alienated due to perceived and actual difficulties in access and navigation. This includes inaccurate information on the websites and the necessity of the carer telling their story more than once. Anecdotally, this has resulted in limited numbers of referrals being made to those services – rates that are significantly lower than VCSN members would have expected, given referral rates to existing services.

Lack of formal supports:

The final obstacle identified by the sector is the lack of formal supports to assist carers to cope with behaviours of concern. Carers across the aged, disability and mental health sectors consistently report the difficulties and at times the danger in which they are placed when caring for someone at home. Service providers may not employ staff trained to support people with behaviours of concern. Organisational Occupational Health and Safety policies prevent many service providers from sending staff to assist in situations where a recipient has displayed or has a record of displaying behaviours of concern. Respite facilities frequently decline to admit people who display aggressive or violent behaviours. Mental health organisations too often appear to ignore behaviours of concern to carers, or are too under-resourced to respond appropriately. Behaviours of concern by recipients frequently pose the greatest threat to sustainable caring, as carers are continuously confronted with frightening / threatening situations, which create fear, stress and injury. It is also important to note that carers' concerns need to be considered on an individual basis and according to the carer's individual context. Behaviours which challenge one carer, (e.g. incontinence) may not have a similar impact on another, but in another context may contribute to a carer's burnout or relinquishment of the care recipient.

System Complexity:

The health and community services sector is complex. Diverse sources of funding, each with their own unique inclusions and exclusions, varying regional service pathways and differing service cultures and worker styles create a service access and delivery system that frequently confuses carers. In many instances, lack of service cohesion creates the need for carers to tell their "story" multiple times which carers find frustrating and unnecessary. "I just want them (the government and agencies) to be as efficient as we have to be!" (Carers Victoria, 2015)

Opportunities to enable sustainable caring

Natural supports:

As has been outlined, there are a number of challenges facing carers in the current reform context. There are, however, a number of opportunities to explore in developing capacity for sustainable care – both from the perspective of natural supports and a service driven response.

In the current environment many carers have been left feeling confused and unsure of supports available now and for the future. Moving forward, there is the opportunity to better enable carers with the knowledge to access, navigate and self-advocate within the reformed service system. This will be essential in assisting them to sustain their caring role, ensuring they know how to articulate and where to access the support that they need, when they need it.

The provision of timely, accurate and comprehensible information is a key strategy underpinning this area of health promotion. Research shows the provision of information alone is not enough (Fry, 2003). People need opportunities to think about and talk through the information so that they can relate it to their individual or family situation. Community education programs can be highly effective in building the capacity of carers with access to information regarding the reforms and changes that will impact them. This includes regular access to information sessions, accompanied by printed material and guidance on navigating online information systems. Adequate access to translated materials and interpreters is also critical not just for equity, but for increasing the likelihood of sustainable change for carers from non-mainstream communities.

As has been mentioned earlier, social isolation is a major challenge for carers. Providing opportunities to connect with others carers, and maintain meaningful social connections through peer and carer support initiatives is a vital support that will further enable the sustainability of caring relationships.

Service responses:

Whilst the government has committed to continued support of carers, it is important the sector, including carers, provides input into how this may look. The implementation of a National Framework and Screening Tool, with clear and transparent guidelines regarding eligibility is essential to ensure that services can adequately and appropriately support carers to maintain and sustain their caring roles. Further to this, it is critical there are clear and adequate responses and referral options for those carers who do not fit the eligibility criteria for funded services to ensure that they do not fall through the gaps.

It is well recognised that carers are the experts in their own lives, and often in the lives of those for whom they care. Thus, it is crucial they are included in the design of carer support services to ensure these are provided in ways that best meet carers needs and enable sustainable caring now and into the future. This co-design approach is critical. Furthermore, services will need to work flexibly and collaboratively with carers and *with each other* to develop the best possible service responses. It is vital that we encourage and generate a cohesive and collaborative service sector that can effectively plan with, inform and support carers.

As Federal and State Government reforms impact and the service system adjusts to cater to trends towards consumer rights and responsibilities, it will be important that carers are enabled to sustain themselves in their caring roles. This will be best achieved by retaining current service system functionalities such as capacity building, training and education to help develop resilience and personal resources, encouragement of social connectivity, enablement of peer and informal support and supporting carers to develop and manage their individual support plans. Empowering carers to access, navigate and advocate within the changed service system is and will continue to be imperative. This will require well trained and informed staff, with knowledge of the reforms that supports provision of correct and timely information.

All carer situations are unique and the provision of flexible service provision will continue to be fundamental in enabling carers to sustain their caring roles. Service provision must continue to respond to individual carer needs, take a holistic approach to the carer’s circumstances. The needs of secondary carers must be recognised, and supported with access to services.

The VCSN believes that the current raft of system reforms provides an opportunity to move away from a reactive approach to an early intervention framework. The reforms present an opportunity for early engagement with carers in all phases of their caring role and an awareness of efficient referral pathways and effective interventions. A health promotion approach would provide the capacity to increase community awareness building, enhance productivity in providing health and service information to communities and the development of preventative programs.

Conclusion

In conclusion, the VCSN acknowledges the opportunities to enhance carer support in a holistic, consumer focussed manner under the current suite of reforms. This paper seeks to highlight what is working well for retention in a future carer services framework, and what the current system lacks or fails to address adequately, suggesting a number of recommendations in the executive summary. We believe that a system that addresses these issues will be well on the way to providing consistently robust and timely carer support, reducing the risks to carer health and wellbeing, financial status and social connectivity. In doing so, we will ensure that carers’ contributions to our nation’s economic and social health and wellbeing continues.

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