

Designing the new integrated carer support service:

Submission from BrainLink Services Limited

About BrainLink Services Limited

BrainLink Services Limited (formerly Brain Foundation Victoria) is a Victorian not for profit, community based provider that has been in existence since the early 90's.

BrainLink works to build the capacity of carers and families to deal with daily living challenges and complex behaviour arising from Acquired Brain Injury and Disorder. We are dedicated to provide carers and families an enhanced quality of life.

Acquired Brain Injury and Disorder (ABI and D) includes Motor Neurone Disease, Multiple Sclerosis, Stroke, Brain Tumour, Brain Cancer, Parkinson's disease, Muscular Dystrophy, Huntington's disease, Dementia, along with head injuries from a punch or fall and concussion? These are all Acquired Brain Injuries that can happen to anyone! They do not discriminate!

Currently BrainLink has **1300 carers** registered with the organisation to coincide with **8000** families we touch through our Information services and hospital liaisons (CLO).

BrainLink has strong relationships with the neurological organisations to cover all ages of carers, NDIS or non NDIS, great referral systems and combined knowledge. This is a strong example of how we work together and respond to significant numbers across multiple sectors.

Encouraging the interface specifically between Health and Disability to work best to provide a continuum of services to carers and families is something we do as a matter of course.

BrainLink 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".

BrainLink has reviewed the Delivering an Integrated Carers support service – A draft model for the delivery of carer support services, and provides the following comments by way of response.

- Supportive of the objectives and delivery principles articulated in the framework. The types of supports proposed are considered appropriate.
- Gives multiple entry points that allow the carer to choose the most appropriate/preferential mode of seeking support/information.
- The targeted education element is a valued addition, with this role being difficult to achieve under the current structure. A dedicated and valued focus in this area will ensure that education becomes an integral part of the suite of services available to carers.
- We agree 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.

However, after intense consultation with the carers and families BrainLink works with we wish to highlight the following concerns that:

- The proposed 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.
- There is an overt reliance on technology and may not mean the 'best' solution for carers. There are many older carers/others who do not use computers and do not have access to them or know how to use them.
- Important to note that on line is not the best solution for carers who find themselves suddenly impacted by the devastating outcome of caring for someone with an acquired brain injury or disorder. Help needs to come from knowledgeable objective supporters and staff who know what they might need as the carer will not know! In those early days carers will not emotionally be able to access on line information
- It is proposed that much of the information will be available on line. But having to read and scan vast amounts of information that may or may not be relevant, to find the right solution is time intensive and often unsatisfactory.
- 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.
- Many older carers will probably disengage from the service.
- Many, if not all of the services, appear to require contact through the national number, rather than through the regional hub or localized services. The local approach to service delivery to Carers ensures a deep understanding of the system and the ability to seek solutions from the sector for carer's issues outside the norm. This ability to be responsive to the need at hand is key to effective carer support.
- The proposed model does not appear to have any outreach capacity and appears to be passive in carer identification and support. This will add to the burden of proactive early intervention and support.
- The regional hubs have not been identified. This may impact large areas supported inadequately by staff who will be challenged to maintain an effective working knowledge of local needs and options and being knowledgeable about condition like acquired brain injury and requirements to meet the impact.
- It is unclear around funding arrangements for peer support groups and whether specific funding will be made available for this purpose, what will be funded and how local the response might be.

Providing support to carers as early as possible is crucial and BrainLink has successfully implemented a community liaison officer (CLO) in 3 major hospitals as an effective and efficient means of raising awareness for a carer early in their caring journey. Each CLO touches base with a minimum of 200 carers per year (600 in total per year). There is a strong partnership with the acute hospital sector to identify and focus on carer and family needs whilst hospital staff care for the patient. BrainLink is part of the discharge plan and follows up with the carer once patient leaves hospital. During this person to person contact carers are:

- Empowered to navigate the system
- Referred to access a variety of networking and learning opportunities to become socially connected and understand importance of self-care
- Provided tools and education for the practical management of daily living challenges and complex behaviours of people with Acquired Brain Injury and Disorders
- Actively working with BrainLink to build community connections in their specific geographic locations to seek interventions as early as possible

For BrainLink carers assessing need can be challenging as the trajectory as a result of an Acquired Brain Injury or Disorder is often complex and devastating. Carers don't understand it and have no idea what they will require or even the questions to ask or know about to find relevant information. BrainLink staff are 'experts' in the Acquired Brain Injury field well experienced with significant knowledge and as a result are able to guide and support at the pace of each individual carer. The CLO and carer officers also have substantial awareness of services and supports to refer families to.

The high burden of care for someone with complex needs and behavioural issues associated with brain injury and disorders is very real. Without support breaks, opportunities to socially connect and meet others in similar situations, carers themselves develop chronic health conditions. Carer's health is a very big issue. It can only get worse!

Education sessions about the role of caring, keeping healthy, emergency planning etc. are vital but in BrainLink's long experience best delivered face to face in small groups.

Carers require real people to walk them through their situation to help them and their loved ones live a good life as well as assisting them to plan for the future in very difficult circumstances.

BrainLink strongly believes that carers should be provided an allocation of funding or support entirely and specifically for themselves to ensure that they can continue to care without compromising their own health. Carers need services to sustain them throughout an exhausting caring role both physically and emotionally.

Thank you for the opportunity to provide feedback and BrainLink looks forward to continuing to consult in the coming months.

Submission by:

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