Response to the Draft Services Concept

All of the proposed Support Service Concepts are parts of what makes a whole, each is needed in a Carer’s journey at some stage. The timing of each service requirement would be, and is, different, for each Carer as every caring situation is different. Some Carers require maximum assistance while others choose not to ask for any assistance at all. Some Carers ask for assistance for a short period of time and then “move on” others require weekly, monthly or 6 monthly assistance, based on their own needs and unique situation. At no time can assumptions be made, Service Concepts have to be available, flexible, in different forms and combinations over different periods of time. The attempt package up any supports for Carers is an impossible task, although for some a regular Respite service may appear to be sufficient, in time all of the other concept services may also be required. The assumption that a “service provision” model, used with/for people with disabilities, frail aged or medically unwell, does not fit with Carers who generally are well! Hence the question, why do Carers need an in-depth assessment? Carers are in our communities and require a “community Model” to meet their needs, NOT a medical or disability Model. Support needs to be variable, flexible, accessible, community connected, provided by community staff, connected to community. This sort of approach is an early intervention, preventative approach, not based on disability and illness where “professionals” are needed to “diagnose and treat.” Carers aren’t sick, but do need support.

Awareness

Successful awareness raising is a difficult activity, even the most experienced marketers rarely get it right. Over the last 20 years our experience in referrals received for our Carer Support Services have consistently been 60% through word of mouth from family, friends or acquaintances, 10% each from local community Organisations, Doctors, Health professionals, Carer Associations or Respite Centres! National Media marketing may help however the relational community connections continue to be the most valuable referral source. For Young Carers success has come through speaking to Staff at Schools at least yearly to keep them informed of the hidden needs of this group of Carers. Early intervention is most effective through the 2 methods mentioned above as at times Carers present prior to diagnosis, particularly for Dementia. Our Medical system is not Carer friendly at all, it is left to the community to be, and provide the support systems, so community awareness raising at the local level may be the best approach.

Information Provision

Information for Carers has to be available through experienced local mentors or even phone or online who have a wide range of knowledge. As stated in the introduction all Carers are unique and all require specific information tailored to their own specific situation. This Information Concept is a vital component of the whole support system and has to be provided skillfully by people who understand Carers, not other services who are aged and disability or mental health focused experts.

Intake

A *“way to ensure that intake is of direct benefit to carers is to limit its utilisation to those times it is* *necessary” (*p27) As mentioned above Intake should happen at the local level where full information can be gathered on needs, based on a real understanding of the unique carer situation. A “shallow” Intake of very basic information may be done online or phone but anything more will require the Carer repeating their “story” again. Intake is a sensitive time and any barriers put up will prevent early intervention and may even lead to delaying access to supports and then possible crisis.

Education

Clear evidence of the need for carer education is provided in the draft Service Concept. This is true for our experience too, particularly education in Dementia, Autisim and Mental Illness on a 6 monthly rotation for each at a Group, at a face to face level and has been effective and life changing. Carers may attend each 6 month Course (a day per week over 3-4 weeks), less for Mental Health. Generally these education Courses are accessed from agencies like Alzheimer’s Australia, Carers Aust or other providers at minimal cost, using our local Carer Support Centres as the venue and booking agent. Carers can choose how often they attend, from experience a Dementia Carer may attend the 2 Courses per year for up to 6 or 7 years because the progress of this disease will mean constant change, adaption, and new advice/information will be provided on each occasion. These face to face education options for Carers also have a Peer/Support Group outcomes where Carers meet other Carers and relationships are built. We believe an online option should also be available and will be utilized by a good percentage of Carers, however the socially isolated will benefit even more from a local, face to face model too.

Peer Support

Peer Support is once again an option for carers, it is but one component of a range of services Carers can choose, when they, think it is appropriate. When Carers meet and share stories in any setting, particularly Support Groups, they reduce the costs of facilitators and educators because carers themselves become the informers, educators and practitioners for and to each other. These connections then flow out into the community and have immeasurable effect across our communities. The community benefits because carers are strengthening each other, helping each other cope and reducing the costs of services significantly. Community development, early intervention and prevention at its best. The use of staff “Mentors” for Group facilitation is a cheap option at even a national level. The measurable and immeasurable outputs from Peer Support Groups far outweigh a professional staff person spending 2 hours with 10 Carers individually, the Carers themselves do the work! Peer Support a cheap and vital Concept service for Carers.

Needs Identification and Planning

Assessment should be “self”, despite the commonly known fact that “Carers minimize”. Self assessment can “be shallow” in that, only the basic information needs to be collected as the Carer themselves do not generally have a disability nor medical or aged condition. As a consequence they only need to give basic information, to please the funders/organisation. Once “registration” has happened time needs to be taken with Carers to develop a plan, remembering that ALL caring situations are different and a range of services and support will come into play based on disability, local services available etc, etc. A unique plan (if that is what Carers want) that takes many issues into account like, is there or isn’t there any family support, community support, programs, respite, doctors, health professionals, dozens of variables. Online or phone information gathering can be done at a shallow level, however eligibility, self assessment and goal based planning need to be done at a face to face level. Highly qualified staff is NOT a necessity, however staff (Mentor) with a good knowledge of local services and supports can assist is developing plans.

Multicomponent intervention

All the Concept Services mentioned above are part of the puzzle with the Multicomponent intervention concept. The use of Mentors/Coaches to assist Carers by taking time to listen, plan, and assist them through the maze of human services. Encouraging education, providing information, low level counselling, introduction to peer support groups, social activities and Respite. Initial linkages to Carers by Mentors/Coaches can be intense for a 3 month period. Carers often then are capable of moving in and out of the Carer Support System/Service Concepts at their own choice and timing. Carers at times may not access the service for months or even years, they often just need to know WHERE they can seek assistance if needed, that alone can give them peace of mind, assisting them to cope in their caring role.

Summary

The approach for supporting Carers should not be based on medical or disability model. Carers are part of our communities and some times need extra support to maintain their health and caring role. At times they do need information about the disability or illness, and services and supports for their cared for and them selves. This information can come from help lines and websites however goal setting, emotional support, respite, peer support, mentoring, all multi component interventions should be face to face. The model should not be seen as case management (which needs Degree qualified staff) but as a community model where support comes from both mentors (Diploma/Certificate qualifications) and peers as well as referral to other organisations that specialise in the support of the “cared for”. Community based support work is carried by the members of the community not exclusively by paid professionals. This approach keeps the costs of running an Integrated Carer Support model down because Carers are not case managed, they themselves move in and out of the System (Carer support) at their own choice. Choosing from the concepts described above, when and where most appropriate for their own situation, not dictated by “qualified experts”. They can be mentored to develop a plan to reach a goal, and then they manage it. Because all Carers are different and so are their circumstances, all disabilities and health issues are different and so are the required supports, a ridged model of support can not be utilized. Carers want choice and flexibility, guidance and full control, some one to talk to, support in their community. A community model is cheap and effective, and there appears to be enough money in the Commonwealth funded Carer Services (Appendix B and C) if distributed through a Community based Integrated Carer Support Model would be enough to meet the needs of hundreds of thousands of Carers around Australia. No new funding would be required.