Department of Social Services

Designing the new integrated carer support service – a draft service concept for the delivery of interventions to improve outcomes for carers

SUBMISSION

14 June 2016

ATTRIBUTION

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ABOUT ACSA

Aged & Community Services Australia (ACSA) is the leading national peak body for aged and community care providers. It represents church, charitable and community-based organisations providing housing, residential care, community care and home support services to older people, younger people with a disability and their carers.

ACSA members provide care and support in metropolitan, regional, rural and remote regions across Australia.

The ACSA Federation is made up of the following members:

➢ Aged & Community Services NSW & ACT (ACS NSW&ACT);

➢ Aged & Community Services SA & NT (ACS SA&NT);

➢ Aged & Community Services Tasmania (ACS Tas);

➢ Aged & Community Services Western Australia (ACSWA);

➢ Aged & Community Services Australia - Victoria (ACSA Vic);

➢ Aged & Community Services Australia - Queensland (ACSA Qld).

Mission-based and other not-for-profit aged care organisations are responsible for providing services to those older Australians who are most in need. As at 30 June 2015 not-for-profit organisations delivered 57.1 per cent of residential aged care services and 81.6 per cent of home care packages in Australia.[1]

These organisations are visible and highly accessible in the community and as a result, the public relies on them for service, support and care. The broad scope of services provided by ACSA's membership and the leadership they display gives it unique insights into the challenges and opportunities that come with the ageing of the population.

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[1] Based on Commonwealth of Australia (Department of Health) material (2015). '2014-15 Report on the Operation of the Aged Care Act 1997', Canberra, 49, 38.

INTRODUCTION

ACSA supports the development of an Integrated Plan for Carer Support Services comprising the Carer Gateway which was established in December 2015 and a new integrated carer support service system. ACSA considers it essential that carers have access to a simple, consistent and robust system which facilitates the wellbeing of carers and the wellbeing of the people they are caring for.

The first component of the design of the new integrated carer support service system is the draft Service Concept which sets out what services could be delivered and why this will assist carers. Feedback from ACSA's members on the draft Service Concept is set out against each of the parts of the discussion paper.

FEEDBACK ON DISCUSSION PAPER

PART A. STATEMENT OF NEED [PAGES 7-20]

Who are our carers? [pages 7-11]

All carers are unique and 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" while 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 at all times.

It is important to note that people may not recognise themselves as carers and if they do it is often with reluctance as if it somehow takes something away from the relationship they have with the care recipient. People are more likely to identity as a carer only when the caring role has become more significant and the natural relationship between a husband and wife or parent and child for example becomes challenged.

Reaching hidden carers is a significant challenge, therefore carer intervention and education programs need to reconsider language around carer/caring in order to reach those people at the very early part of their carer journey.

Young carers have not been identified or recognised under this section of 'Who are our carers'. Young carers are highlighted later but should also be recognised in this section.

Current carer support policy framework [pages 12-13]

It seems there is too much focus on definitions rather than on outcomes and what those outcomes are. It seems we are trying to have an each way bet; is it for the carer or the care recipient. Sometimes it simply can't be for both. Carer support is just that.

There are too many diverse carer scenarios to neatly and effectively fit them all into 'packages' where the outcomes are focussed on the care recipient. This isn't saying that the two aren't linked because they are and can be. It is saying however the reasons behind why carers require support in

their own right differs to that which binds them to the continuity of care and support required by the care recipient. Further, how will the ongoing recognition and support for young carers, carers from a range of culturally and linguistically diverse (CALD) communities, Aboriginal carers, working carers, and carers from all of the other unique communities that exist, be addressed within this direction.

The current fragmentation of available carer support services is a reflection of the government working in silos across the aged, mental health and disability sectors from which policy has developed and individual funded programs have emerged.

ACSA members strongly support and encourage a coordinated and integrated approach to policy and funding models of carer support services across all community and health sectors, making it easier for carers to access support regardless of the health condition, age or disability of the care recipient in their care.

The current directions re respite within the National Disability Insurance Scheme (NDIS) which is to remove it completely, leaving it unrecognised and therefore unfunded, (including the Information, Linkages and Capacity Building (ILC) Policy Framework) completely devalues carers and the need for support in their own right outside of their caring role. There is no assessment of carer need anywhere within the NDIS or Commonwealth Home Support Programme (CHSP) processes.

Current carer support centres, including Commonwealth Respite and Carelink Centres and Carer Associations are well established, linked, trusted and engaged with local carers, providing identifiable and a local access point for carers seeking support, education, information and counselling.

It needs to be made clear how the integrated carer support service will differ from existing Commonwealth Respite and Carelink Centres.

Drivers for change [pages 14-18]

ACSA members are concerned that key drivers for change including the Commonwealth Carers Recognition Act (2010) and the National Carers Strategy (2011) have not been acknowledged. Both aim to increase recognition and inclusion of carers, provide information, access and services to carers, including enabling economic security, health and wellbeing and access to education and training. It is important that we utilise past and present resources, knowledge, expertise and skills to build on and improve existing carer support services, rather than reinventing or diluting what has been achieved in the past.

It is important to ensure carers are eligible for services in their own right. In the past access to carer support has often been linked to recipients' eligibility for programs (see page 16 re current complexity); and carers of ineligible recipients in future may need more support (eg. NDIS participants vs unfunded individuals; those who may fall between program areas eg people with younger onset dementia etc).

The attempt to package up supports for carers is an impossible task although for some a regular respite service may appear to be sufficient; however in time all of the other concept services may be required. A "service provision" model, used with/for people with disabilities, frail aged or medically unwell does not fit with carers who are generally 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 and not a medical or disability model.

ACSA members agree that preventative care is important to carers; however the challenge surrounding the lack of self-identification and high numbers of 'hidden' carers makes this extremely

challenging to deliver. Members support carer preventative services but not at the cost of other carer support services such as emergency respite.

ACSA members agree that the lack of informal care into the future will challenge health and community care and believe we need to look at the reasons for the lower propensity to care. This needs to include exploring strategies to encourage informal care, such as incentives to care e.g. tax breaks, housing, health concessions and increasing carer financial and health benefits. Early intervention programs need to ensure easy access to health care so that people are encouraged to support an ageing parent or unwell partner or child.

A shift towards prevention [pages 18-19]

Carer needs for different supports will vary over time according to their individual situation. An evidence based approach should be taken allowing a suite of proven supports to be designed which carers can choose from according to their goals at the stage they are at.

Carer support needs to be variable, flexible, accessible, 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.

Members believe this approach partnered with the provision of support when carers require it (i.e. emergency respite/counselling) will enable carers to be well informed, connected and supported sustaining their caring role.

Guiding principles [page 20]

Members have expressed concerns about recent reforms shifting the focus of service delivery to the care recipient, rather than working in partnership to meet the needs of both the carer and the person in receipt of care. This presents serious risks for carers and further highlights the need for an integrated support system that is flexible, innovative, tailored and includes carers.

It is important that an integrated carer support system continues to retain the strengths and positive aspects of the current system (e.g. emergency respite), uses existing infrastructure (local identifiable networks, staffing expertise and knowledge) to deliver a national carer focus integrated (aged, disability and health care) support system.

PART B. THE DRAFT SERVICE CONCEPT [PAGES 21-48]

<u>**Awareness [pages 23-25]**</u>

Design considerations set out in the discussion paper are:

- **What would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?**
- **In considering support for young carers, to what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner?**
- **Should more resources be directed towards raising awareness about young carers (and carers in general) in the healthcare sector, rather than schools?**

Successful awareness raising is a difficult activity; even the most experienced marketers rarely get it right. Over the last 20 years referrals received by one carer support service have consistently been 60% through word-of-mouth from family, friends or acquaintances with 10% each from local community organisations; doctors; health professionals; and Carer Associations/Respite Centres.

A national carer awareness campaign would 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, followed by information and support.

It is important to be able to reach those carers who do not acknowledge their role and also to identify carers early so effective preventive supports can be put in place. This can be done even before someone is thinking of becoming a carer. Multiple avenues and methods should be used to raise awareness and these should be targeted depending on the audience.

Capturing carers at Department of Human Services when they apply for carer benefits; and incentives for GP's/hospital staff/HR workplaces to refer carers to the Carer Gateway. The Carer Recognition Act is excellent but needs to broaden its reach to encourage further recognition and inclusion of carers.

Carers WA delivered a number of pilots in schools to raise awareness and identification of young carers which was very effective. This initiative could be embraced by education departments in partnership with the Department to increase identification and support to young carers.

A National Carer Gateway, like My Aged Care, is not always an appropriate referral pathway for Aboriginal carers. Aboriginal carers like most Aboriginal people who are aged or frail, are not accessing My Aged Care and local Aboriginal providers are not receiving the volume of referrals they did prior to the introduction of My Aged Care. Aboriginal people prefer face-to-face assessments conducted by local Aboriginal providers.

Support for young carers should involve consultation with education departments, Aboriginal Education Consultative Group, Aboriginal Education Officers, Aboriginal TAFE Coordinators and Aboriginal University Units to develop short term programs to identify young carers and the role they may be playing within their families. Also to inform young Aboriginal people of what a carer is and to provide information on services available in their local areas. Ideally, this would include tools for workers eg teachers and a tool for students.

Culturally appropriate resources should be made readily available through Aboriginal outlets such as Aboriginal Medical Services, Aboriginal Health Liaison Officers, Local Government Aboriginal Liaison Officers (council based), Aboriginal Sector Development Officers, Aboriginal Ability Linkers, NSW Lands Council Network, Koori Mail, National Indigenous Radio Service, National Indigenous Television, and Central Australia Aboriginal Media Association.

Information provision [pages 25-26]

Design considerations set out in the discussion paper are:

- **While information is available through carer organisations today, as well as the Carer Gateway, would individualised recommendations be of benefit when carers are undertaking or receiving other services?**

This Information Concept is a vital component of the whole carer support system and has to be provided skillfully by people who understand carers and not as an add-on to other services provided by experts in other fields.

Individualised recommendations are crucial to receive other services. One size does not fill all and personal circumstance varies from client to client. Aboriginal people prefer holistic approaches but are aware that this is not always possible, therefore individual information provision must be tailored to a carer's individual needs.

The Carer Gateway, like My Aged Care, is not always an appropriate pathway for Aboriginal carers and not everyone has the resources or tools to access the Gateway. The Carer Gateway is limited in reaching rural and remote locations. It does not take into account people who do not have technology to access the Gateway and literacy and numeracy have not been taken into account.

The majority of Aboriginal carers will rely on an Aboriginal provider they have developed a relationship with which may not be a specific carer organisation. They generally tend to go to an Aboriginal person/worker or provider they know, one who understands their individual circumstances and can assist them. There should be a "no wrong door" policy. Aboriginal people should be able to access services from a provider that they have developed trust and a relationship with. As with My Aged Care, many Aboriginal people will not reach the referral stage when calling the Carer Gateway, as they may not want to disclose their individual circumstances to someone they perceive as Government. This is due to lack of trust from past Government policies. The person they are caring for may be a Stolen Generation member, or may have been impacted by the intergenerational trauma caused by past policies and may not want the carer to disclose information to someone they do not know or trust.

Intake [page 27]

Design considerations set out in the discussion paper are:

- **Are there ways to make intake a more beneficial process for carers?**
- **To what extent would intake be required to facilitate access to peer support or education?**
- **When should intake be a mandatory process?**

A "*way to ensure that intake is of direct benefit to carers is to limit its utilisation to those times it is necessary*" (page 27 of the consultation paper).

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/assessment 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. Direct referral to a carer support service who understand what carers require (not just respite and counselling) is essential for early intervention which generally leads to supports that may be "preventative" or reduce carer and

client stress and crisis.

The WA Assessment Framework (WAAF) includes a carer screen as part of the standard assessment for Home and Community Care (CHSP) services, which assists to identify and register carers at the early part of their carer journey. Department of Human Services, MyGov should automatically initiate a referral for people applying for a carers benefit or pension to the Carer Gateway – an integrated system. Streamline access to one gateway for carers and clients rather than through My Aged Care for clients and Carer Gateway for carers. Services providers should be funded to guide both carer and client through the process.

Special arrangements need to be put in place when there is a young carer involved or the clients' needs are substantially higher than the carer is able to provide safely.

The national system is not a culturally appropriate pathway for Aboriginal people. In Aboriginal culture, it is culturally inappropriate for a young male carer to be showering his mother or female family member, and vice versa.

Whilst we strongly support this process, care needs to be taken when deeming a process 'mandatory'. There should always remain some flexibility available to take account of individual circumstances to ensure no one is denied a necessary support.

Education [pages 28-29]

Design considerations set out in the discussion paper are:

- **How can we encourage carers to access education support?**
- **If education were to be offered online, how can we encourage carers to participate and complete an education programme?**
- **How can the future Integrated Carer Support Service help carers to be aware of, and access education which may be relevant to them outside of these carer focussed supports?**

Education will be more accessible if it is tailored and targeted to individual circumstances.

As the discussion paper mentions, education and support is often not seen as a priority by carers until crisis point. Integrated carer support services should be accessible 24 hours via the Carer Gateway for carers looking for immediate support when a crisis hits.

Members reported that the Dementia Education and Training program available through Commonwealth Respite and Carelink Centres had positive benefits for carers, but it was challenging to get people to attend. Making it easier for carers to attend training includes offering affordable and flexible respite options.

Education of carers could be encompassed in the provision of carer support services so it becomes "on the job training" rather than an education program. Education also needs to be part of health programs and while people are in hospital, a shared care/partnership approach, as well as part of the care recipient assessment process. Each intervention is an opportunity for education/information sharing across aged, disability and health care.

Evidence of the need for carer education is supported by experience particularly education in dementia, autism and mental Illness if provided on a 6 monthly rotation for each either in a group or one-on-one. Experience has shown that this education has been effective and life changing. Generally these education courses are accessed and provided by agencies like Alzheimer's Australia, Carers Australia or other providers at minimal cost, using local Carer Support Centres as the venue

and booking agent. Carers can choose how often they attend, from experience, a dementia carer may attend 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. Some may attend only once or even once each year. These face-to-face education options for carers also have a peer/support group outcome where carers meet other carers and relationships are built.

To enable carers to access online education programs, carers need to be provided with adequate accessible technology or an appropriate place where the technology can be accessed. Carers could be encouraged to participate by offering online social networks and incentives (entering a draw prize on completion); promoting health benefits, prevention of injury; and safety for carer and care recipient; and course units could contribute to formal qualifications (career opportunities).

Throughout Aboriginal culture face-to-face is more appropriate than other forms of support. An Aboriginal carer would prefer education and training programs to be delivered by an Aboriginal provider. Clients and carers should be encouraged to participate in social support groups for peer support. Access hubs with information regarding education to improve a carer's social and psychological outcomes through support from government departments eg Health; Aboriginal Medical Services; First Nations National Congress; young carers camps such as Kamp Kookaburras; forums; support networks eg. Kari; Aboriginal Child, Family and Community Care State Secretariat; Secretariat of National Aboriginal and Islander Child Care; National Aboriginal Community Controlled Health Organisation; Aboriginal Education Consultative Group.

By ways of promoting outside of the normal avenues, such as with religious groups, community hubs, local schools, media advertisements – television, newspapers, magazines. Possibly running educational groups and peer support groups in conjunction with programs running for the client. The information provided needs to be culturally appropriate, easy to read and enticing for Aboriginal people e.g. have Aboriginal art and Aboriginal people promoting supports.

Peer support [page 30]

Design considerations set out in the discussion paper are:

- **What are some of the tools or supports which could assist in delivering peer support to a broader base of carers in a cost effective manner?**
- **How can a peer support model be designed which encourages carers to participate and remain engaged?**
- **Should peer support be a service able to be accessed without pre-conditions or structure processes?**

Peer support should be one component of a range of services carers can choose when they think it is appropriate and should be able to be accessed without pre-condition or structured processes.

Offering peer support which has flexible delivery options such as online, phone, face-to-face is important. Many carers find it difficult to commit to a set series of sessions so allowing flexibility may engage more carers. Providing respite options for the care recipient or providing peer support opportunities which include both carer and recipient would make peer support more appealing to some carers.

Peer support for Aboriginal people may simply mean having informal meetings with other carers, family, local community nurse or doctor, keeping them informed about other support that is readily accessible. Community group transport could be accessed to transport carers who are isolated. Many Aboriginal people/carers would meet informally to "see what's going

on" prior to committing to specific groups.

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. This is a demonstration of community development, early intervention and prevention at its best. The use of staff "Mentors" for group facilitation is a less expensive option even at 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, because the carers themselves do the work. Well facilitated peer support is a less expensive and vital concept service for carers.

Needs identification and planning [pages 31-32]

Design considerations set out in the discussion paper are:

- **To what extent do you think goal based planning should be used at the assessment stage of the process?**
- **Would a goal based planning approach be worthwhile?**
- **To what extent should self-assessment form part of the future model?**

Needs identification and planning should be linked with intake and part of the prioritisation process.

Goal based planning could be used in the assessment stage to help the carer identify what is needed. However goal setting is a foreign concept to some so support may be needed through the process. Some people may not see a benefit in goal setting so it should be done on an individual need basis.

As mentioned earlier the WA Assessment Framework (WAAF) includes a carer screen as part of the standard assessment for Home and Community Care (CHSP) services, which assists to identify and register carers at the early part of their carer journey. The carer needs identification tool including goal based planning would benefit carers greatly in both preventative care and future planning e.g. planned respite care, counselling etc, sustaining the carer's role. Looking into the future and needs of the carers should be paramount to the planning future.

However, there is some thought that whilst goal based planning brings with it many benefits, there may be some limits if the goals fails to take account for planning for times of crisis – therefore carers would benefit from skilled support in developing their goals.

Self-assessment should form part of the model as carers are best placed to understand their situation. Self-assessment should be included in the first stages and then updated at intervals as required. Self assessment can "be shallow"; in that, only basic information needs to be collected as the carer does not generally have a disability, medical or aged condition. Once registration has happened time needs to be taken with carers to develop a plan, remembering that caring situations are different and a range of services and support will come into play based on disability, local services available etc. A unique plan will take many issues into account like, is there or isn't there any family support, community support, client 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 local face-to-face level. Highly qualified staff is not a necessity; however staff (mentors) with a good knowledge of local services and supports can assist in developing plans.

A multicomponent intervention (including carer mentoring, financial support and respite support) [pages 33-41]

Design considerations set out in the discussion paper are:

- **How can we ensure these supports are allocated to those carers who will benefit the most from them?**
- **What should be the criteria by which this is determined?**
- **How can we help carers to use funds appropriately without large administrative burdens on carers or providers who may be assisting them?**
- **When would a coaching programme be most effective for a carer?**
- **Should coaching be a mandatory part of a multi-component support model? Or should mentors be able to determine whether the carer has the capacity to forgo coaching until another time?**
- **Will moving to more of a consumer directed model, where funding is attributed to an individual carer result in unintended effects? What might these be and how can they be mitigated?**

Multicomponent interventions should be the preferred approach to supporting carers using those interventions which have been shown to be most effective and make them available either individually or as a flexible package of carer support services based on need.

Multi-component supports should be allocated at the time of need and not when its reached crisis point. Consumer directed respite care should be just that, when the client needs it, not when someone else determines it is needed. If a provider notices that respite is needed, it should be offered but it's the carer's decision whether to accept a service.

Individual circumstances must be considered in allocating supports including the health and wellbeing of the carer (injuries, mental health etc); the number of people in the carer's care; the severity of health condition/disability of the people in the carer's care; the length of time in the caring role; and access to ongoing informal and formal supports.

Carers should not have access or amount of service limited because of location and associated additional costs eg for transport etc.

Members recommend that direct support for carers, respite etc, should be allocated as a package for the carer and could be as a direct payment to purchase these supports to meet the individual carer's needs. The allocation could be graded into portions used for direct respite/education/mentoring etc and the carer could chose to use individual or bundled components.

CDC is consumer driven; therefore the use of funds would be prioritised to the carer's most urgent need. With the CDC respite program, providers requested receipts from carers and this worked well.

Coaching should not be mandatory. It should be offered and available at different times through the caring journey so it can be taken up when it best suits the carer – rather than becoming a burden and just something that needs to be completed in order to access other supports the person may want. Mentors could assist in helping carers see the benefits of coaching.

Ensuring some funding is available on a consumer directed approach is supported for those who wish to take on managing their own budgets, however this should be provided as an option and not a requirement as an unintended consequence may be carers opting out of accepting service or support if it is going to require additional work on their part.

Some carers may not use the funding as required and may prefer to forgo services to save for something of benefit to the care recipient rather than him/herself.

Many short term respite services are not adequately resourced to provide high level care limiting respite options for those often with the greatest need. More short term, emergency and flexible respite is needed.

Refer to benefits and limitations identified in KPMG evaluation of consumer directed care in 2012.

Counselling [pages 42-43]

Design considerations set out in the discussion paper are:

- **What counselling programmes and techniques would be beneficial in reducing carer burden?**
- **Could these be delivered to a broader group of carers through telephone or online channels?**

A range of programs and techniques is important.

Face-to-face is crucial and is the best technique for Aboriginal people. Telephone and online options are supported but carers should also have the option of face-to-face sessions. Increased access to technology and specific apps for carers will particularly suit the next cohort of carers.

Out of hours counselling support should be available being offered at a time suitable for the carer – including late at night.

Respite should be paired with counselling services and made available for the care recipient to ensure the carer is able to attend. Telephone and online support is often seen as a lower priority for the carer and alternate care arrangements for the care recipient will often not be made. Therefore the carer may be distracted or interrupted or simply not participate limiting the benefit received.

Supporting all carers [pages 44-46]

It is positive to see special needs groups such as LGBTI identified. However there is no detail in the paper as to how the needs of these groups will be addressed.

Whatever carer support options are offered, they must be tailored for the audience with materials provided in different languages, at different venues, by different service providers.

Carer supports need to be able to extend across, during and after working hours. This has sometimes been a shortcoming of existing respite services.

Support for carers should not necessarily end when the physical caring role is no longer required (ie death or movement to a residential facility). The carer still needs a short period of support to adjust to their new circumstances.

ACSA encourages the concept of a 'no wrong door' policy for carers to seek information and enquire or register for services. This recognises that many carers will still go to their local service provider to 'enquire or register for service'. This is particularly true for people in rural areas and for many clients from special needs groups. Aboriginal people and CALD people will go to a familiar place to enquire about services. It is therefore important that the system allows for this to continue and that service providers are not financially penalised by having to do this additional work without payment.

An Aboriginal carer may be the carer of a Stolen Generation Member. The last place a Stolen

Generation Member may want to live is in an institution like setting, such as residential aged care which is too familiar with where they spent their childhood. Therefore an Aboriginal carer is protective of the information they provide to a Gateway. They would prefer a face-to-face assessment or support with an Aboriginal organisation/worker that they have built a relationship of trust with.

Providing integrated support [pages 47-48]

Members note that not one service model (i.e. online) suits all and recommends that the integrated carer support service system be made available locally as well as nationally. Members also advise that awareness and information needs to be available broadly including through Centrelink, Regional Assessment Service, My Aged Care, Primary Health Care, Tertiary Health, Schools (Young Carers).

Other comments on part B

Members recommend that the integrated carers support model build on the successes of existing Commonwealth Respite and Carelink Centres and Carer Associations so that the benefits achieved by these existing programs are not lost.

OTHER COMMENTS ON THE DISCUSSION PAPER

Overall a comprehensive high level document. However it lacks specific detail; for example regarding future funding for particular service access.

Previous consultations have been held looking at carer supports which offered four different service models and respondents favoured the hub and spoke model to retain local supports. It is important that the learnings from these earlier consultations are not lost and are used to help inform this process.

The approach for supporting carers should not be based on a medical or disability model. Carers are part of the community and sometimes need extra support to maintain their health and caring role.

At times they need information about the disability or illness and services and supports for the person they care for and themselves. 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 to the greatest extent possible.

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 and volunteers not exclusively by paid professionals. This approach reduces the costs of running an integrated carer support model because carers are not case managed. Carers move in and out of the carer support system at their own choice.

Carers are the experts in their own lives and are capable of choosing from the concepts described, when and where most appropriate for their own situation, not dictated to by "professionally qualified experts". They can be mentored to develop a plan to reach a goal and then they manage it.

All carers are different, and so are their circumstances; all disabilities and health issues are different and so are the required supports. A rigid packaged model of support cannot be applied under these conditions. Carers want choice and flexibility; guidance but full control; someone to talk to; and support in their community.

More specifically, the Carer Gateway should interface directly with My Aged Care to minimise the number of different platforms that carers need to negotiate.

There needs to be assurances about the quality of training of staff working on the Carer Gateway.

There doesn't appear to be detailed referral pathways for consumers to access services such as Seniors Rights Service, Guardianship Services or elder abuse helplines etc.

Also clarity is needed re the future of access to advocacy for carers (NCAP; National Disability Advocacy Program) as well as the future of funding for organisations which support carers in other ways (e.g. ARAFMI; Carer NSW).