Carers Australia

Submission to the draft Service Concept

‘Designing the new integrated carer support service’

June 2016

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

Carers Australia is the national peak body representing the diversity of Australians who provide unpaid care and support to family members and friends with a:

- disability,
- chronic condition,
- mental illness or disorder,
- drug or alcohol problem,
- terminal illness,
- or who are frail aged.

Carers Australia believes all carers, regardless of their cultural and linguistic differences, age, disability, religion, socioeconomic status, gender identification and geographical location should have the same rights, choices and opportunities as other Australians.

They should be able to enjoy optimum health, social and economic wellbeing and participate in family, social and community life, employment and education.

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Introduction

This submission has been prepared on behalf of the National Network of Carers Associations ('the Network') which is made up of Carers Australia and the state and territory Carers Association. The Network works collaboratively to lead change and action for carers across Australia. Our shared vision is an Australia that values and supports all carers.

The submission is based on the understanding that:

- The draft Service Concept provides the broad service framework or skeletal structure of the proposed service model but it does not address detailed service delivery. Having said that, we have made references throughout this response to particular programs delivered by the Network to illustrate points and to provide current service examples.

- More detailed consideration of how the proposed service would be implemented, including more detailed design features, proposed assessment instruments, evaluation and roll out, will be the subject of later stages of project development.

- The draft Service Concept for Integrated Carer Supports does not at this stage focus in detail on the degrees of integration with the larger sectors and systems that carers have to deal with for themselves and the people they care for, such as the NDIS and elements of aged care.

- It addresses services rather than social security payments.

While we have framed our submission to respond to each of the design considerations raised in the draft Service Concept, we note that there is considerable overlap across the principles of best practice service design and delivery that we have outlined for each of the discrete services identified in the paper. This makes for a certain amount of repetition and so we have referred back to other responses where appropriate.

Some General Comments

- Overall, the ‘draft Service Concept’ is a well-balanced document which identifies the range of needs that carers have, provides a good summary of what carer supports currently exist, and reflects the feedback received through the Department’s co-design activities.

- The Network supports the Guiding Principles for the new Integrated Carer Support Service System which are outlined in the draft Service Concept, particularly the Department’s commitment to retaining the strengths of the current system. While we acknowledge that the new system will have a carer focus, we note that often a whole of family approach will be necessary to ensure the best outcomes for carers are achieved. The Network recognises that a balance will be required between the principles of a nationally consistent, locally responsive service system, whilst also achieving a system which enables innovation and flexibility. We also support the approach to address both current and emerging carer needs, which we understand will include early intervention as a priority.

- We strongly contend that supports should be available to all carers regardless of whom they care for.

- One point of particular concern is the paper’s strong focus on upholding the sustainability of care as the main reason to provide supports to carers. While this is obviously an important rationale for the provision of carer supports, it is equally important not to reduce carer supports to a by-product of addressing the needs of the person being cared for. Carers have a right to access services to support their own needs whether or not the outcome is to sustain unpaid caring over the long-term. As acknowledged in the *Carers Recognition Act 2010* (Cth):[1]

  - All carers should have the same rights, choices and opportunities as other Australians, regardless of age, race, sex, disability, sexuality, religious or political beliefs, Aboriginal or Torres Strait Islander heritage, cultural or linguistic differences, socioeconomic status or locality.
  - Children and young people who are carers should have the same rights as all children and young people and should be supported to reach their full potential.
  - The valuable social and economic contribution that carers make to society should be recognised and supported.
  - Carers should be supported to enjoy optimum health and social wellbeing and to participate in family, social and community life.
  - Carers should be acknowledged as individuals with their own needs within and beyond the caring role.
  - Carers should be supported to achieve greater economic wellbeing and sustainability and, where appropriate, should have opportunities to participate in employment and education.
  - Support for carers should be timely, responsive, appropriate and accessible.

- The Network supports the broad range of services identified in the paper, but it is not clear as to the extent to which individual advocacy for carers is included.

- We also note that many carers need access to specialist support, either because they belong to a particular carer cohort (e.g. young carers or older carers) or because they are struggling with issues that can be attributed to the caring role (e.g. losing their job). Further consideration will be needed as to how these supports will be provided in the context of the new model, especially for communities where there are few services specific to their needs and where there are still considerable barriers to accessing basic health or welfare services. In particular we encourage consideration of:

  - Culturally appropriate engagement with, and support for Aboriginal and Torres Strait Islander carers and carers from culturally and linguistically diverse backgrounds.
  - Appropriate engagement with and support for LGBTI[2] carers.
  - Support for carers transitioning from the caring role (where detailed knowledge of other local services will be important).
  - Special assistance for carers in rural and remote areas (e.g. transport and outreach).
  - Flexible supports for working carers.
  - Supports for carers wishing to enter or re-enter the workforce after their caring role has ceased or reduced.[3]
  - Supports for young carers in the family and school environment.

- There could be a stronger emphasis on carers' choice in taking on or ceasing the caring role, and that carers' needs can change significantly throughout the caring journey.

- The role of volunteers in the delivery of services to carers needs to be examined and defined in relation to the new integrated service system.

- The draft Service Concept seems to primarily focus on providing services to individual carers. It is frequently the case that the caring role extends beyond a single carer in the context of family and friend relationships. Therefore, the new model of Integrated Carer Supports should include

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[1] https://www.legislation.gov.au/Details/C2010A00123

[2] Lesbian, Gay, Bisexual, Transgender and Intersex

[3] An example of some of the work being done in this area is the NSW Government-funded 'skillslink2work.com.au' website which aims to encourage carers to think about how the skills, knowledge and experience they have developed as carers can be used to gain employment.

options to support families who wish to receive services in a whole-of-family (or family of choice) context, rather than individually.

- The draft Service Concept highlights that there is a lack of reliable and robust evidence as to the effectiveness of some carer supports. The Network believes that the new Integrated Carer Support Service provides an opportunity to embed improved data collection, performance indicators and evaluation tools into the new service landscape.

- The function of the proposed national carer needs identification tool needs to be considered carefully; i.e. whether it will be for needs assessment only, or whether it will be used to determine eligibility. A nationally consistent eligibility assessment tool could create a sense of entitlement and it would need to be clear what that entitlement is. It might also make some carers who are currently receiving services ineligible to continue receiving them. Alternative support arrangements would need to be available to these carers.

Comments against Design Considerations

Awareness

Q1: What would be the most effective and efficient means of raising awareness for individual carers early in their caring journey?

- It will be important to reach carers both in their everyday environments and at points where they are first likely to become aware that they will have a caring role, or the caring role changes (for example, is intensified).

Everyday environments may include:

- Workplaces; The goal of Carers Australia's Work & Care Initiative is to raise the awareness of employers to assist them to identify carers in their workplace; as well as to provide information directly to employees with caring responsibilities to help them self-identify as carers and to alert them to carer and community supports that will help them combine work and care.

- Schools and other educational institutions; This could include outreach programs to schools to raise awareness of the caring role, that there may be young carers in the school environment and, more specifically, to assist teachers to identify young carers and point them to support services. See also response to questions 2 and 3.

- Health Services: Including primary care (General Practitioners), specialists, acute and sub-acute hospitals, pharmacies, and other allied health professionals. See service examples below.

    - The Carers NSW Carer Survey 2014[4] found that GPs were the most commonly accessed source of formal support.
    - According to the Australian Bureau of Statistics 2012 Survey of Disability, Ageing and Carers (SDAC), 89.5 per cent of primary carers visit a GP for their own health at least once every 12 months. Over 40 per cent of primary carers see a medical specialist for their own health at least once every 12 months.
    - Hospital admissions can represent a critical time in the care giving experience; sometimes the start of the caring role or an increase in care needs. The amount of information shared with the carer, the degree of choice about taking on caring responsibilities and the level of planning and services available are important factors in helping carers to prepare for or continue their role.

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[4] https://www.carersnsw.org.au/research/survey

  - It is important that the range of health professionals who come into contact with carers on a regular basis are familiar with the concept of ‘caring’, understand the needs of carers, and have the capacity to refer them to supports. Establishing referral links between carer services and Primary Health Networks (PHNs) will also be important.
  - Carer awareness should also be incorporated into the professional training of health, mental health, aged care and disability workers, and carer input could be valuable in this setting.

- Carer consultants and carer peer support workers located at health service gateways are also a means of informing health sector staff on carer needs and raising awareness of service pathways for individual carers early in their caring journeys. These models have been utilised to great benefit in the mental health sector and could be extended across PHNs.

SERVICE EXAMPLE: Carers WA ‘Prepare to Care’ Hospital Program

The ‘Prepare to Care’ Hospital Program provides information and support to those family members and friends who will be providing ongoing care to patients both during a hospital admission and following being discharged from hospital.

The program provides information relevant to family carers both during and after a hospital stay including support services which may be of assistance following discharge from hospital. The program also aims to provide hospital staff with resources to provide carers with more information, a better understanding of the requirements of care and linking of the carer to relevant services to contact.

Carers WA have developed a resource containing places for carers to record information provided by hospital staff, plus information on navigating the hospital stay as well as on support services for the carer, and the person with care needs. The resource can be found here: http://www.carerswa.asn.au/carers-wa-services/prepare-to-care/carers/.

Carers WA also provide education and support to hospital staff in identification, support and referral (via an interactive online form) of family carers.

This program is currently operating in 22 hospitals across metropolitan and regional WA.

SERVICE EXAMPLE: Carers NSW: Integrating carer information with Healthdirect

As part of the *NSW Carers Strategy 2014-2019,* Carers NSW partnered with Healthdirect to integrate carer information with information on care recipient services online through Healthdirect.

The goals of the project were to:
- Ensure that existing Healthdirect content was addressing the needs of carers.
- Enhance landing pages to align to the scope of the *NSW Carers Strategy*.
- Ensure relevant content is displaying in aggregated search results.
- Encourage other organisations to link to Carers NSW carer content.
- Promote Carers Week on the Healthdirect homepage.

Healthdirect will continue to update carer content on an ongoing basis.

SERVICE EXAMPLE: Carers Victoria 'Carers ID' program
Includes:

- Staff carer information presentations
- An easy e-Referral Process & Carer Call Back (enables referrers to securely request a qualified Carer Advisor to contact the identified carer).

This is a successful pilot project in Victoria that efficiently and effectively facilitates referral of carers from health services to carer support services. It has also highlighted that while carers may not take up support services immediately following a referral, a proactive approach can help to identify current and future needs of carers that may be followed up later.

- The inclusion of carer information on the websites of condition-specific organisations is another avenue for awareness raising. Often the first place a carer will look when they find themselves caring for a person with a disability, mental illness, chronic condition or terminal illness is a website which will explain the condition, how it is likely to progress, how it can be treated and services which might be accessed. This may include incorporating information about the carer journey alongside, or incorporated with, information about the condition in question, and identifying the types of services the carer may wish to access along the way. This is discussed further in questions 9 and 10 below.

- Many carers do not identify themselves as 'carers' and will not seek support even if they need it. This applies especially to carers from Aboriginal and Torres Strait Islander and culturally and linguistically diverse (CALD) backgrounds. Community development approaches (such as awareness raising through local engagement and education) can be particularly effective in reaching these carers.

Q2: 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?

- The Network believes there would be value in seeking information and advice from the education sector to identify the best way to liaise with schools and to establish an awareness raising program about young carers. The education sector has experience in developing similar programs around other issues such as domestic violence and bullying.

- While the Network is well placed to assist in developing the content of such a program (and indeed has developed such resources in the past), its implementation and dissemination across schools is best guided by the education sector itself. Such an awareness raising program about young carers would need to be targeted to students, teachers, school nurses and other student welfare staff.

- Increasing the ability of education, training and employment bodies to identify young carers is also important. This could be achieved through the provision of professional development training, utilising young carer advocates to facilitate and encourage schools to increase links with community agencies that can assist young carers, building better linkages with community support services and parents/guardians. Young carers should also be identified as an 'at risk' group with specific needs and barriers to participation within Commonwealth education, training and employment policies and programs.

SERVICE EXAMPLE: Carers WA Schools Program (no longer funded)

This program was funded for two years by the WA Department for Local Government and Communities and involved Young Carer Officers employed by Carers WA working with schools to identify young carers in the classroom which included delivering education sessions to staff and in classrooms. A specific referral form for schools was developed and is still used. The program was independently evaluated by the funding body and identified positive outcomes.

Q3: Should more resources be directed towards raising awareness about young carers (and carers in general) in the health care sector, rather than in schools?

- The Network strongly believes that this shouldn't be a matter of either/or. Awareness raising initiatives for young carers should be focused on both schools *and* the health care sector.

- One of the most effective and efficient means of raising awareness is within a range of health settings, but also in places where young carers (and carers in general) spend a lot of their time, including primary, secondary and tertiary education settings, social media platforms, workplaces and Centrelink offices. Awareness raising efforts through the justice system may also assist in outreach to some young carers, particularly if they're caring for someone with an alcohol or drug problem. Young carer awareness could also be incorporated into young people's mental health promotion programs.

- Young carers' vulnerability can vary in ways that are reflected in the broader community. For example, young carers who are refugees, those who live in rural and remote areas, LGBTI young carers or Aboriginal and Torres Strait Islander young carers, may all experience additional barriers to accessing a range of supports and services.

Information provision

Q4: Feedback from co-design participants to date has indicated that information provision must be tailored to a carer's individual situation or it is of limited value. While information is available through carer organisations today, as well as the Carer Gateway, would individual recommendations be of benefit when carers are undertaking or receiving other services?

- Tailored information and individual recommendations will be of benefit both when the carer is accessing information and services for the person they care for, as well as when receiving carer-specific supports for their own needs. While general information can often be disseminated at the national level, individualised recommendations will often be more appropriately generated at the local level. Tailoring information to individual needs can be achieved in a number of ways:

    - <u>Tailoring to the condition of the person being cared for:</u> Incorporating carer information on professional and health consumer websites to ensure there is information for the carer as well as for the person with the condition.

    - <u>Tailoring to different demographics of carers:</u> This may include carers who identify as Aboriginal and Torres Strait Islander, carers who come from culturally and linguistically diverse (CALD) backgrounds or carers who are from LGBTI communities. Individualising information for these groups may go to the language used, or to where and how the information is disseminated; for example, cultural centres or other community gathering places, or by employing community placed peer educators, peer carer consultants and peer carer support workers in community specific health or carer support settings.

  - Tailoring to the service being accessed: Carers often look for, and receive information whilst accessing mainstream and other carer services such as peer support groups. Integrating individualised information and recommendations into these settings can be a useful way to ensure carers are well-informed.

  - Tailoring through a needs assessment: An assessment tool can also assist in identifying what is of most concern to the carer at any point in time and may be repeated over time as changes occur.

- Carers can be overwhelmed with information, particularly when they first become a carer, when they're often focused on the immediate needs of the person they're caring for. It's therefore important that carers have many opportunities to receive information and recommendations throughout their caring journey. For those who are not seeking information about carer services in the first instance, it's important that they are encouraged to re-visit either the Carer Gateway or their local carer organisation in the future, if their information needs change.

- It will also be important that the range of information available to carers is not just limited to the types of services available for both the person they care for and themselves, but that it also covers *how* to navigate the various service systems. This may include information about the service responsibilities of different departments (e.g. health, disability, social security) or information on what services are offered by a range of service providers and how to gain access (e.g. when a formal assessment is required). Information of this nature can help to build carer's capacity and confidence in accessing supports.

- Information also needs to be provided in a variety of modes to cater for all preferences, as predominantly web-based information will exclude many carers. For carers who speak languages other than English, who are just starting out, who don't know what they don't know, who have low levels of literacy and numeracy or limited IT skills, who can't afford a computer and associated costs, who have difficulty using computers because of visual impairment or other disabilities or who are just not part of the internet generation, it is vital not to reinforce the digital divide or to put people off at the very first instance.

Intake

Q5: Are there ways to make intake a more beneficial process for carers?

Q6: To what extent would intake be required to facilitate access to peer support or education?

Q7: When should intake be a mandatory process?

The intake process:

- Intake may need to vary depending on the individual circumstances of the carer. Initial contact and registration could vary from 'light touch', with only the most basic information needing to be provided, through to immediate contact with a trained counsellor or emergency respite care for those carers in urgent need.

- There will also need to be provision for carers to choose their preferred communication method (online, phone, SMS, email etc.) and for those who do not want a service referral immediately or who decline services following referral to have proactive follow up.

- Intake should not be mandatory for all carers. Carers should always have a choice about becoming a ‘registered’ carer with support services when they are accessing information, peer support or education services only. The requirement to gather data should not prevent or delay service and support being provided to a carer. However, intake may need to be mandatory to access services such as planned respite, financial support or coaching/mentoring or counselling where access is based on assessed need. It is also important to identify needs that may not be apparent to the carer, for example the need for future planning when the person being cared for has early onset dementia.

Key inclusions:

- To reduce the extent to which carers are required to re-tell their ‘story’ and provide the same information to multiple agencies or organisations, the information collected through a central intake process could be made beneficial to carers by sharing it with other providers where necessary, with the permission of the carer. Shared information would be beneficial for carers interacting with the NDIS, My Aged Care and the new Digital Mental Health Gateway as well as to services (carer specific or mainstream services) to which they are referred.

- The Network supports the proposition in the draft Service Concept that one way to make the intake process more beneficial for carers could be to register their emergency plans with service providers. Other similar options include assisting carers to register for a MyGov.au account for access to a ‘My Health Record’, an Advanced Health Directive or Guardianship Orders.

The approach:

- The expertise and specialist carer knowledge of staff as well as *how* the intake process is conducted will be important factors in whether carers experience any benefit from it. For example, not rushing the carer and giving them time to tell their story and feel listened to will have the dual purpose of providing emotional support whilst gathering information. Conversely, if information is demanded of the carer in a manner which makes them feel rushed and not listened to, the intake process may actually add to their level of stress and anxiety. The intake process must therefore be handled sensitively.

- Intake also needs to be culturally sensitive so people feel safe seeking information without fear of judgement or discrimination. Community groups and representatives from a diverse range of communities should be consulted on the development of intake materials where relevant.

- It is important that both workers responsible for intake and carers themselves understand why certain information is being asked for. This will assist the intake process.

Education

Q8: How can we encourage carers to access education support?

Promotional avenues:

- There are a range of avenues through which carer education initiatives could be promoted including through:

  - Condition-specific organisations and their websites.
  - Commonwealth Respite and Carelink Centres (CRCCs) – or whatever form these may take in the future.
  - Carer support organisations.

  - NDIS: planners and Local Area Coordinators (LACs) who come into contact with carers need to be aware of the educational and training needs of those who care for a person with disability, and have the knowledge to refer carers to these services and supports.
  - Through My Aged Care: those undertaking assessment through the Regional Assessment Service (RAS) or an Aged Care Assessment Team (ACAT) need to have an awareness of the importance of carer supports and to make appropriate referrals to education and training for carers of the frail aged.
  - Targeted promotion to culturally specific, Aboriginal and Torres Strait Islander and LGBTI communities.

- Feedback from the Network also highlights that many Carers Associations encourage carers to engage in education through peer support activities. This may involve integrating an education component into a peer support group (for example, through visiting speakers/trainers), or simply via word-of-mouth from the testimonials of other carers or service providers

Targeting carer educational needs:

- The Network stresses that one of the key ways to ensure that carers are interested in educational supports is by ensuring the supports are informed by, and meet, the identified needs of carers. Some Carers Associations do this by engaging in a co-design process with carers to involve them in the content development which helps to increase the likelihood of uptake. Carer training packages which have come out of these processes (and which have received good feedback) include self-advocacy training and education focused on maintaining carer health and wellbeing.

- Educational topics typically in high demand for carers include those which are focused on understanding service systems and knowledge and practical skills such as mental health first aid. Other educational topics which are also important include those focused on negotiating and managing personal budgets, such as the Carers SA NDIS Project outlined below.

- Carer education also needs to be provided to those who have lower literacy or who may speak a community language other than English. Materials for these groups need to use appropriate terminology, be simple and easy to understand and not discriminate against carers due to cultural background or disability. This means working directly with a variety of other organisations and community groups to co-design education materials so that they are appropriate.

- Free or low cost education that provides recognition in the form of awards, certificates of completion, or attainment of competency are also seen as important in encouraging carer participation. So too is the provision of accredited training which can link to employment opportunities (see Carers Queensland service example below).

- The provision of training for carers which is recognised by *jobactive* providers as contributing to any participation requirements for receipt of Newstart Allowance may also increase carer engagement in education.

SERVICE EXAMPLE: Carers Queensland Accredited Training

Carers Queensland is a Registered Training Organisation (RTO) and delivers Certificate III in Community Services and Certificate III in Aged Care. Carers Queensland's delivery strategy includes:

- Face to face training one day per week for each cohort of students.
- Email, phone and Skype support in between weekly classes.
- Where necessary, the delivery strategy includes home visits if students' caring role means they are unable to attend class for a couple of weeks, or they get behind in their course work, due to caring responsibilities.

- Support and guided referral from Carers Queensland regional staff.
- Job readiness support and training.
- Option to complete basic computer skills training, and ‘Job Club’ training, which includes modules such as Resume and Interview Preparation, Interview Skills and Dress for Success.
- Where necessary, language, literacy and numeracy (LLN) support is provided (including by qualified CALD staff in regional offices when needed).

SERVICE EXAMPLE: Carers SA Creative Ways to Care

Creative Ways to Care is a training program delivered to carers of people with dementia across South Australia. The program teaches ways to creatively respond to changing behaviours, reduce or prevent problem behaviours, improve communication and improve day-to-day life. Its delivery involves a number of stages, including:

- an overview of dementia and behaviour
- practising strategies such as soothing the senses, music, reminiscence and creative arts
- tools and resources to use these strategies at home.

SERVICE EXAMPLE: Carers SA NDIS Project

Carers SA has developed the NDIS Project, run from its Limestone Coast branch in Mount Gambier. This was in response to carers of children with a disability struggling to find adequate disability supports in the local area.

The project gets together groups of carers to increase their buying power, and then connects them with service providers from across the State (65 providers to date). Through their collective buying power, carers can negotiate with providers and encourage them to enter the region.

Q9: If education were to be offered online, how can we encourage carers to participate and complete an education programme?

- The Network’s experience with online education has demonstrated that a ‘blended’ approach to learning is beneficial and has greater uptake than stand-alone online learning. However, there will be some carers who prefer only to engage in online learning, particularly if they are unable to leave the person they care for alone for any extended period of time. Promotion for this group of carers could still be through the avenues identified above, but particularly through the websites of condition-specific organisations. This is explored further in question 10 below.

- A key consideration of whether online education is appropriate will obviously depend on the complexity of the type of education being delivered and how it is delivered. For example, technical training through information sheets combined with video may be quite straightforward and accessible; examples might include wound management or safe lifting techniques. In other cases an interactive mode may be required which can also technically be delivered on-line but is more complex and resource intensive. In other cases, face-to-face education may be more beneficial both because it provides an opportunity to discuss in detail individual situations and appropriate responses and because it provides an opportunity to identify and share experiences with other carers. A case in point may be education for carers who are dealing with challenging behaviours.

- It is also important to remember that a number of carers may not be able to access on-line information and will need to be able to access what is available on-line in face-to-face settings or through hard copy publications (see response to question 4 above).

Q10: How can the future Integrated Carer Support Service help carers to be aware of, and access education which may be relevant to them outside these carer focused supports?

- Carer service providers, such as the Network, already provide a range of advice which might be considered as education around a range of issues which go beyond the services they offer. These include providing advice about the workings of:
  - Health services
  - Housing and tenancy
  - Advocacy
  - Guardianship and administration issues – Public Trustee and Public Advocate
  - Issues with complaint procedures
  - Educational supports and funding options
  - Assistance with paying utilities accounts
  - Advice on sources of financial support both within and outside the social security system
  - Accessing transport
  - Employment issues due to their caring role

- In the case of accessing condition-specific information about how to care for family members or friends, many health consumer organisations offer excellent advice for carers. Some examples include Alzheimer's Australia, MND Australia, MS Australia and Raisingchildren.net.au (which has some very useful educational information for parents raising children with autism). Many carers will find this information of their own accord when researching the condition of the people they are caring for. However, a section of the Carer Gateway identifying such sources of educational information would also be of assistance. Carer service providers can also point carers to relevant websites.

- With respect to the NDIS, the supports offered under Information, Linkages and Capacity Building (ILC), as well as serving people with disability, should also be able to point carers to mainstream services for themselves and those they care for, as is outlined in the ILC 'Commissioning Framework Consultation Draft'[5]. We would expect that Local Area Coordinators (LACs), planners and providers should be aware of both specialist and mainstream services that may meet a range of carers needs and effectively link carers to them.

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[5] Pg 15, http://www.ndis.gov.au/community/ilc-home/ilc-commissioning-framework-consultation

Peer Support

Q11: 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?

- There are a range of peer support models that should be made available to carers including:

  - Peer support for carers at a particular stage of their caring journey (e.g. starting out, end-of-life care, and transition to care outside the home).
  - Peer support for people in specific communities.
  - Online and tele-link support groups.
  - Training for peer facilitators (e.g. Train the trainer model).
  - Face-to-face support groups with professional facilitation or co-facilitation between a peer and a professional).
  - Peer led education.
  - Paid carer peer models and volunteer models may both be of benefit.

- For a number of carers online peer support may be preferable as it provides anonymity, is easy to access (for those who don't have time to travel to face-to-face meetings), or is more cost-effective (where finding replacement care would be prohibitive). For those who live in a rural or remote area, it also enables access to a support which may not be available otherwise. For carers who are regular users of social media and who are comfortable and familiar with these platforms, online peer support may also be a more natural way of interacting with others.

- Some carers will also want peer support from carers who are caring for someone with the same condition. Face-to-face peer support of this kind may not always be feasible if there aren't enough other similar carers in the same area. In these instances online peer support may also be preferable.

- Carers from culturally and linguistically diverse (CALD) backgrounds may also find that there are not enough other carers in their area from a similar cultural background to offer peer support groups in different languages. Online groups may also prove a useful alternative in this situation. Alternatively, face-to-face may be the preference for some CALD carers where they can access it in their locality.

- Some carers may wish to seek support among LGBTI communities. For those living outside capital cities, online groups may be a useful alternative to face-to-face.

- However there are also disadvantages to online peer support and we have some concerns about how it would be managed. For example the need for forums to be moderated for content would need to be considered to ensure that inappropriate comments were removed. Similarly, forums may need to be monitored to ensure that individuals who are experiencing considerable distress receive appropriate referral in a timely manner.

- In other cases, face-to-face peer support will be preferred. One of the main advantages of face-to-face peer support is the opportunity it provides for carers to meet other carers and the impact this has on reducing their social isolation. See the example of the Dubbo Koori Carers Yarning Group below. Face-to-face peer support enables the carer to take time out of the home and to meet other carers in person. Furthermore, some carers may not feel comfortable utilising online forums to speak about personal issues, or simply may not have the technical knowledge to use them. It is therefore important that face-to-face peer support remains an option.

- As mentioned above, another advantage of face-to-face peer support is the opportunity to combine it with education and training and the fact that it can act as a conduit to use other services.

- For some types of peer support, carer support providers can use volunteers, for example by linking former carers with current carers to share their expertise and experience.

SERVICE EXAMPLE: Carers NSW Dubbo Koori Carers Yarning Group

Carers NSW partners with a number of other organisations in Far Western NSW to run a carer support group for Aboriginal carers. The group runs at no cost to members and provides important respite and social support as well as critical information sharing about services, including the NDIS. The group also organises occasional social and cultural outings for members.

SERVICE EXAMPLE: Carers ACT Keeping Families Connected – a counsellor led, peer support group for carers and families of people with mental illness and co-morbidity

This program delivered by Carers ACT provides participants with practical advice on caring for someone with a mental illness or co-morbidity. Experienced counsellors use group therapy techniques and work closely with carers to develop strategies to cope with mental illness and its impact on family relationships. The five-weekly sessions combine education, group mentoring, information and relevant advice.

Mental health carers report a significant improvement in understanding the mental health system, increased knowledge of available supports and services, awareness of self-care and understanding of how to support the person they care for and increase family safety.

The program can be designed for specific carer cohorts, e.g. young carers, male carers, female carers and carers from diverse cultural backgrounds. Carers are asked to pre-register for the program to enable the counsellor facilitator to identify the carer’s main caring issues and ensure the group structure provides a positive outcome for all group members.

Q12: How can a peer support model be designed which encourages carers to participate and remain engaged?

- As well as offering the range of peer support models described above, the experience of the Network has also been that diversity and innovation (and in turn carer engagement) can be encouraged by resourcing carers wherever possible to start, sustain, maintain and expand peer-led groups. See the two service examples below.

- There are also examples where carers and the people they care for may wish to participate in peer support together – for example younger onset dementia groups or Parkinson’s disease groups.

SERVICE EXAMPLE: Carers NSW *together* program – support groups for carers of people with a disability in NSW

The *together* program provides opportunities for 350 support groups for carers of people with disability in NSW to be linked with each other and an organisation and receive financial and other assistance. It is funded by the NSW Department of Family and Community Services, Ageing, Disability and Home Care and provides:

- Central coordination of support groups, including regular communication.
- A small amount of funding to assist with group costs, such as venue hire, administration, resources and guest speakers.
- Training and support for group facilitators.
- Capacity building for organisations working with support groups.

SERVICE EXAMPLE: Carers NSW Carers Craft Studio in Coffs Harbour – an example of how seed funding can enable innovation and establish best practice.

A craft studio was developed by Carers NSW in 2013. Since its inception the Carer Craft Studio has been running in the Coffs Harbour office once a week. It aims to increase the health and wellbeing of carers by providing a weekly craft meeting as a positive respite experience for carers to get together, share ideas, be creative, build confidence and self-esteem and to participate in generational and cultural mentoring.

The Studio creates a variety of benefits for carers, including the ability to earn extra money through the sale of craft items, a place to make gifts for family and friends and work and education opportunities. Long-term friendships may be formed reducing social isolation and improving the mental and physical wellbeing of carers.

Q13: Should peer support be a service able to be accessed without pre-conditions or structure processes?

- The Network feels strongly that carers should be able to access peer support without pre-conditions or assessment. It's important that carers should not be required to go through an intake and registration process in order to access peer support as a stand-alone service. This may be the first contact a carer has with a carer support service and it may be through contact with peers that they are encouraged to access other carer supports and therefore become a registered client.

- If peer support involved 'matching' a peer with similar lived experience then an intake process would be useful for both the peer and the carer to ensure that the match is appropriate.

Needs Identification and Planning

Q14: To what extent do you think goal based planning should be used at the assessment stage of the process?

- The term 'goal based planning' may need to be unpacked a bit more, particularly if is to be meaningfully understood by carers. Exactly what would it involve? How comprehensive would it be? What timeframe would be the focus for the goals? We know that in the context of the NDIS, many people with disability, their families and carers have found the term confusing and difficult to answer. It may therefore need to be an optional approach under the new Integrated Carer Support Service.

Timing & targeting:

- Whether goal based planning should be included in the assessment stage will depend to some degree on the answers to the questions posed above. Identifying which individual carers it would benefit most at the assessment stage will depend on a number of factors including: the level of assessed urgency of their needs; how long the caring role is likely to continue; and the extent to which the carer is coping well with caring and is only seeking a specific intervention. There will also be carers who may not be coping well, but who are not ready to undertake a goal based planning process in the first instance.

- Where planning during the assessment stage will be important is where carers are faced with multiple disadvantages or have complex problems. This may include relationship problems, financial need, deteriorating health, unstable employment, multiple care relationships or where the carer is experiencing extreme social isolation.

- For carers who don't identify a need for goal based planning at the time of assessment, it will be important that they're advised that if their situation deteriorates and/or becomes more complex, planning is available and why it would be of assistance to them. Carers who have complex needs or who are in crisis may have a significant need for individual advocacy before they can make longer term plans or set goals.

Advantages of carer plans:

- The development of a plan with carers can offer reassurance and guidance to carers by providing a step-by-step plan to work through problems and to identify solutions. It can also include a focus on prevention, by exploring risk factors in the carer's life that are likely to cause future problems. Having an established plan in place to deal with situations of crisis can also play an important role in how the carer and their family deals with that crisis. For example, a carer plan may involve steps to involve other family members in a discussion about who can assist in the caring role, and assistance with developing an emergency care plan. Planning can also be a process of empowerment for the carer, to help them think about the future, including having an opportunity to put in place a succession plan.

- The experiences from the Network have shown that good assessment in conjunction with *collaborative* planning can help carers achieve their desired goals. The key here is that it should be a carer-led process. For some carers, participating in a goal based planning process will enable them to effectively navigate the service systems and to advocate within them for both themselves and the people they care for. For other carers, it may provide a starting point for them to seek variation to the package of support of the people they care for, so that some carer needs are also able to be met within that individual's funding package. The future Integrated Carer Support Service will need to consider that many carers will require professional support to identify and articulate goals and the supports required to achieve these.

Key considerations for carer plans:

- Carer plans must be realistic and not set up expectations that cannot be met. This goes to both whether supports identified in a plan require a co-contribution that the carer cannot afford, as well as developing a plan for which there is no outside funding.

- The planning process should also take into consideration the carer's other family members, other than the person being cared for.

- There will also need to be consideration of the interaction between support plans for the person being cared for (such as NDIS plans or Home Care Packages) and a carer plan developed through the Integrated Carer Support Service. These plans would need to be interrelated to some extent as the ability to achieve goals in one plan may be affected by the efficacy of the other plan. For example, if a carer is required to organise and/or accompany the person they care for to access supports listed in an NDIS plan, this may have an impact on their ability to engage in their own social and recreational activities which are identified in their carer plan. See the Carers WA example below for an example of how the assessment and planning process for both the carer and the person receiving care can be integrated.

SERVICE EXAMPLE: Carers WA 'Carer Wellness at Home' Program

The Carer Wellness at Home Program works alongside other community services to provide in-home support specifically to carers. The program provides:

- Emotional support
- Information about available support services
- Administration support (e.g. assistance with completing paperwork such as Centrelink forms)
- Referral to relevant local carer support services
- The opportunity to access free health checks and social support events through partner organisations.

The program is unique in that it integrates the identification and assessment processes for the client *and* the carer in the same system. As clients are identified in the Home and Community Care (HACC) Regional Assessment Service (RAS) system, the carer is also identified as part of the same system but with a separate dedicated assessment. Carers who qualify are then provided with their own services in the home, funded from a separate source. Referrals to Carers WA result in a home visit and the provision of a range of services as appropriate to the needs of the carer and the development of a carer plan

Q15: Goal based assessment and planning is common to Consumer Directed Care principles, usually in conjunction with a funded package. Given that a carer may not necessarily receive this, would a goal based planning approach be worthwhile?

- Feedback from the Network is that goal based planning can still be a worthwhile activity even if there isn't an individually funded package attached to it. As described above, there are a number of advantages to be gained from planning that go beyond funded supports. For example, for a carer whose goal is to gain employment, their plan may involve identifying options for replacement care (including from other informal supports) and identifying any education and training they require to re-skill. Achieving this goal may not necessarily require supports which are funded through the Integrated Carer Support Service.

Q16: To what extent should self-assessment form part of the future model?

- The Network agrees that self-assessment could form part of the future model, but it won't be appropriate for all carers, or for all services. For example, self-assessment probably won't be appropriate for those who are new to the caring role or for those who are in crisis. This group of carers may not have sufficient self-awareness or knowledge of potential supports. Another risk is that carers may underestimate the impact of the caring role on their life and may play down their own needs. An experienced assessor will be able to draw out a carer's true need for assistance. Similarly, access to a multi-component intervention should not be through self-assessment, but a comprehensive needs assessment.

- Any self-assessment model will need to include ‘triggers’ for access to professional assistance. Triggers could include unstable housing, significant levels of depression, the risk of injury to the carer or people receiving care, or the recent or impending loss of formal or informal supports. The self-assessment tool could therefore include an algorithm which establishes the frequency and urgency of follow up contact with carer support services based on the initial needs identification.

- Another key consideration is that assessment is not only a single point in time event, but an ongoing process as needs change and as carers and the people they care for experience life course transitions and changing patterns of service usage. Options for re-assessment will therefore be key, as well as allowing for a shift between self-assessment to one conducted by a carer organisation as required.

- It’s worth noting that the National Disability Insurance Agency (NDIA) will soon offer a self-assessment option for people’s initial engagement with the NDIS, but with the time to re-visit plans at a later stage. This model will include different options for assistance depending on the circumstances of the participant. The experiences gained from this shift in approach to NDIS assessment and planning could provide important learning for the new Integrated Carer Support Service.

A multi-component intervention

General comments on the multi-component intervention:

- While the draft Service Concept supports the idea of early intervention to reduce the extent to which carers experience crisis, there seems to be a disconnect between this idea and the actual service model which is described in the paper.

- The Network does support the concept of the multi-component support package for some carers, and access to this package should be focused on carers who have the greatest assessed need.

- However, as described in the draft Service Concept, the ‘multi-component support package’ seems to suggest that planned respite, carer mentoring and financial support would only be available through this package, not as separate stand-alone services. If this were the case, only carers found eligible for multi-component support would be able to access any of these three services. Our concern is that the eligibility ‘bar’ for accessing services in this package would be set fairly high, and that carers with lesser needs who only need access to one of these services (for example, planned respite) would miss out altogether. If access to each of these supports is restricted to the multi-component support package, the new service system would fail in its goal to “shift from a reactive response to a planned, preventative model” (page 18).

- It is also unclear whether carers who do access the multi-component support package automatically receive all three services, or just those which are relevant to their identified needs. There is a risk that combining the criteria for different programs will reduce the overall efficiency and efficacy.

Q17: Given that this model is seeking to apply preventative thinking, 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?

- Carer-centred, strengths-based and consistent assessment by qualified, experienced staff is the necessary underpinning to multi-component interventions. There must also be a balance between supports provided to carers with immediate needs and a preventative approach for those who will achieve most long term benefit from timely, proactive supports.

- The criteria used to determine who should get access to supports under a ‘multi-component’ package will obviously depend to a large extent on supply and demand; how many carers can the allocated funding cover and how many carers require this support? This is likely to be a key determinant of both eligibility criteria for access to multi-component supports and potentially different ‘levels’ of assistance within the suite of supports.

- Factors to consider in determining relative carer need should include:

    - The nature and intensity of the caring role.
    - Whether they are the only person able/willing to provide support.
    - Whether the carer and/or other family members are at risk due to the caring role.
    - Whether there are other dependents that are also reliant on the carer.
    - The age of the carer and their own physical and mental health and wellbeing.
    - The level of financial need.
    - Whether the carer has access to other informal supports (e.g. other family members or friends who can assist in the caring role).
    - Whether the person receiving care is accessing other formal supports (e.g. a Home Care Package or the NDIS). However, access to such supports shouldn’t result in automatic ineligibility for multi-component supports. The relevance of access to such supports should depend on the actual level of support provided, and the extent to which it relieves carer strain.
    - The nature of the condition of the person being cared for; whether it is uncertain (e.g. cancer), stable, deteriorating, fluctuates or is improving.
    - The impact of the caring role on the carer and other family members. For example, for those who care for someone with challenging behaviours, are these putting family members at risk?
    - The existence of any other stressors or disadvantages (e.g. housing insecurity, homelessness or relationship breakdown).

Multi-component Support: Financial Support

Q18: How can we help carers to use these funds appropriately without large administrative burdens on carers or providers who may be assisting them?

Advantages & disadvantages of consumer-directed care (CDC) for carers:

- One of the key advantages of carers having complete control over what they wish to spend funding on is that they’ll identify the supports that they feel are most appropriate for their individual circumstances, and they’re more likely to purchase services or equipment that are both effective in meeting their needs and which demonstrate value for money. In this scenario, the relative administrative burden on carers and providers would depend on the level of accountability required of those self-managing funds.

- Another possibility is for carers to be allocated funding for an individual package of supports which dictates the range of service types that can be accessed. The disadvantage for carers in this scenario is obviously less choice and control and potentially a reduced likelihood of the carer being able to implement innovative solutions to different needs. However, there may also be an advantage to carers for those who would be otherwise inclined to spend allocated funding on supports for the person they care for, rather than on their own health and wellbeing.

- As the draft Service Concept points out, one of the key disadvantages of CDC for carers may be the extra time and effort required for people who are generally already time poor and experiencing stress. If the size of the package offered to carers was relatively small, the extra time investment required by carers may not be worth the end result. Alternatively, carer providers can assist carers to manage their packages. However this can impose a large administrative burden on providers unless they are recompensed for this role. If providers' administrative costs are taken out of the package it will have a significant impact on what services and supports can be bought and if the package is relatively small, the whole exercise may not be of much benefit to anyone involved. In this context it is worth noting that provider administrative costs for Home Care Packages and for the management of NDIS packages have been a source of contention.

- Another consideration is that some carers may already be undertaking self- or shared management of an NDIS package of supports or a Home Care Package for the person they care for. While self-managing two (or more) support packages may be ideal for those who want complete control and the ability to integrate supports within each package, this level of responsibility and time commitment may simply be too much for others.

- A disadvantage of self-management of carer supports is that it is likely to increase the social isolation of some carers. Feedback from the Network has highlighted that one of the benefits of carers accessing supports through their state or territory Carer Association is the emotional support provided by staff through their many interactions with carers. A CDC approach is unlikely to offer the same level or type of engagement and emotional support. This experience is also reported in the literature around CDC.[6]

- Many models that produce successful outcomes for carers rely on community development activities that facilitate informal supports and social connectedness. Individually purchased supports can complement but not replace these types of activities.

- Prior experience from the Better Start program and the Consumer Directed Respite Care (CDRC) trial has also illustrated that some carers may 'save up' their allocated funding for emergency situations. This can be problematic if the funding isn't used within the specific time period and may lead to rushed or sub-optimal expenditure as the end of this period draws near.

- Carer needs may be episodic depending on the circumstances of the person they are caring for as well as their own health and wellbeing so it is important not to base funding on what was required historically to determine what may be required in subsequent years. In addition, if a proportion of funds allocated were not used, this may be more to do with the carer's ability to expend the funds (e.g. lack of appropriate services or time pressures) than a lack of need.

Key considerations for carer CDC:

- When looking at the efficacy of CDC for carer supports it's important to consider the key differences between the types of supports offered through the NDIS or aged care, compared to carer supports, and the timing of access. Participants of the NDIS have been identified as individuals who will need life-long support. While this group may not prefer to self-manage their supports initially, they have years to become familiar with the system and to slowly build up their confidence in self-management. The packages of support provided under the NDIS are therefore also likely to be significantly larger than that which would be available for carers. Similarly, those who enter the aged care system are likely to need increasing levels of care as they age, and their package of supports may increase accordingly. Conversely, many carers access supports in an intermittent or one-off manner, and the type and length of support required will often differ over

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[6] Ottman, G, Laragy, C, & Haddon, M (2009) Experiences of disability consumer-directed care users in Australia: results from a longitudinal qualitative study. *Health and Social Care in the Community* vol.**17**, no.5, pp.466-475. Robinson, S, Gendera, S, Fisher, KR, Clements, N, Eastman, C, & Oprea, I (2012) *Evaluation of the Self Directed Support Pilot for Children and Young Adults with a Physical Disability.* For the Department of Communities, Disability and Community Care Services, Queensland, viewed at http://www.sprc.unsw.edu.au/media/File/Final_SDS_Evaluation_report_Aug_2012.pdf

time. CDC for carer supports may be most effective for carers who have relatively stable or consistent support needs, or where an intervention is needed for a defined period of time.

- When considering what form of CDC could be effective for carers and how it could be implemented through a future Integrated Carer Support Service, the experiences to date of the NDIS provide some useful lessons. So far, very few NDIS participants and their families have chosen to fully self-manage their packages, while some have chosen to self-manage specific parts of their package; for example, the purchasing of equipment. It may therefore be necessary to offer a range of options for different levels of self-management to tailor to specific preferences. Such an approach would also help carers to 'dip their toe in the water' and trial partial self-management, while building their confidence and capacity before taking on more responsibility and control. The implementation time frame for this policy should therefore also allow for adequate time for carers to become familiar with and supportive of the concept. The UK experience has demonstrated this could be a lengthy process, so early take-up rates of CDC for carers should not be an indication of potential future support.

- Another key consideration in relation to CDC for carers will be providing them with as much information as possible about the type and level of responsibility they would be taking on, so that they can make an informed decision of whether it's appropriate for their situation. This may include information about the responsibilities involved when directly hiring a support worker, or the costs incurred when using a broker to arrange this on their behalf.

The long and the short of it

- Despite the negative considerations in relation to the implementation of self-managed funding identified above, there is evidence that it can have beneficial outcomes for carers who take it up. It should be an available choice, just as it is in aged care and the NDIS; it should not be mandatory and not remove services from those carers who do not take it up. Carer CDC funding packages should include an additional component to purchase assistance from providers to help manage the package, if that is what carers need.

2. Multi-component Support: Carer Mentoring

Comments about the carer mentoring/coaching concept:

- While the concept of carer mentoring and coaching as a support type is supported by the Network, there is some confusion about what the key purpose of the mentor would be. Is their role to support the carer and/or to assess their capacity and competency to fulfil the caring role? If their role does involve assessment of how the carer is coping, then the mentor would need to be able to identify and refer to services to meet the carer's needs.

- Depending on the purpose of the role, there are also questions about *who* would be best placed to fulfil this role and what the required experience and qualifications should be. While we note (and agree) that mentors need professional training, this need not necessarily rule out peer support. For example, the mental health sector has experience in developing formalised training for peer mentors, including both carers and those who have a lived experience of mental illness. It's also worth noting that, depending on how the role is viewed, establishing the carer mentor/coaching role may also provide employment opportunities for current and/or former carers. The Carers WA Individual Advocacy Program (described below) is an example of the types of assistance that the mentor/coach could potentially provide.

SERVICE EXAMPLE: Carers WA Individual Advocacy program
The Carers WA Individual Advocacy program is designed to assist unpaid carers with complex needs who are in crisis. It provides one-on-one, face-to-face advocacy support to identify the issues that have led to the carer being in a crisis situation.

The advocate uses skills and specialist knowledge to empower the carer to build resilience and to help the carer practise the skills required to get out of the crisis mind set. The advocate also uses team building skills to help bolster the carer's informal support network, whilst also empowering the carer to learn how they can do this for themselves.

The anticipated outcome is a carer who is able, and confident to continue in their caring role, and no longer needs advocacy support or who has learnt how to self-advocate, whilst strengthening and empowering the carer to cope with and manage the issues and stressors of their role.

Q19: When would a coaching programme be most effective for a carer?

Professional carer support is most effectively targeted to carers at different stages of the life course and/or their caring journey including but not limited to:

1. Transition into caring

- Coming to terms with the diagnosis of the illness or disability. This may be sudden or gradual.
- Exploring what it means in terms of changed roles, responsibilities, expectations (lifecycle cultural, personal)
- Learning new roles/responsibilities
- Understanding loss and grief
- Learning what the condition means and what the carer role may involve
- Learning about available services, entitlements, supports
- Making choices re: how caregiving should occur within the family.

If carer mentoring/coaching is available as an early intervention support it may help prevent carers from falling into crisis in the future. However it is unclear how many people would take up the mentoring opportunity at this first stage. Nevertheless, it should be available to carers even at any stage of their caring journey if they think they would benefit from it.

2. Increasing carer needs for support

- When the health of the carer or the person receiving care declines, e.g. dementia; frailty, neurological or malignant illness, and/or the carer is experiencing significant strain/burden
- When informal and family support is removed or insufficient
- When access to services for the person receiving care changes or reduces
- When the carer's expressed need is not shared or accepted by the person receiving care (e.g. access to respite, need for out of home social opportunities).

3. Life course changes

Coming to terms with major changes in life course stage or circumstances; familiar formal services and supports need to be reorganised and replanned. For example:

- transition to school
- transition into or out of employment or adult day activities
- move to 'independent' living or supported accommodation
- dealing with initial respite arrangements
- when new life stage relationships or behaviour issues arise and need to be addressed (e.g. adolescence).
- Other changes in the carer's life such as illness (including mental health issues), separation, divorce, birth of child, career change etc., that may impact on their capacity to care.

4. Fluctuating or episodic carer needs for support

- Episodic changes in health status of the carer or person(s) receiving care e.g. mental illness, neurological illness
- Short-term changes in role demands, circumstances or needs of caregiving family, which require support and/or respite provision
- When care-giving family feels existing formal and informal respite and support arrangements are temporarily insufficient for their needs
- Family conflict (e.g. risks of elder abuse, arguments over who is the primary carer, guardianship etc.)

5. End point transition

Following a move to care outside the home or death of the person receiving care. This is likely to involve:

- loss and grief
- additional role changes/re-learning
- primary support coming from outside the formal care system
- loss of former support from, and relationships with, service providers.

Q20: Given this is intended to be part of a multi-component support model, should this be a mandatory part of the service? Or should mentors be able to determine whether the carer has the capacity to forgo coaching until another time?

- As discussed previously under ‘General comments on the multi-component intervention’, the Network is not supportive of any mandatory provision of carer services. Such an approach could act as a barrier for some carers to take up other aspects of the multi-component support package and would lead to service provision which is not directly linked to the individual needs of carers.

3. Multi-component Support: Respite support service

General comments on the discussion of respite in the draft Service Concept

- While the Network does not dispute that overall respite use is low amongst all carers, there is an important distinction between its low up-take across all carers versus its significant importance to certain groups of carers – particularly those who care for someone with an intellectual disability with challenging behaviours, a mental illness or dementia[7]; see more respite information below.

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[7] Zarit, SH, Kim, K, Femia, EE, Almeida, DM, & Klein, LC (2013) The Effects of Adult Day Services on Family Caregivers’ Daily Stress, Affect, and Health: Outcomes From the Daily Stress and Health (DaSH) Study. *The Gerontologist* doi:10.1093/geront/gnt045.
Neville, C, Beattie, E, Fielding, E, & MacAndrew, M (2015) Literature review: use of respite by carers of people with dementia*. Health and Social Care in the Community* **23**(1), 51-63.
Harper, A, Dyches, TT, Harper, J, Roper, SO, & South, M (2013) Respite Care, Marital Quality, and Stress in Parents of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders*, Paper 1497.
Jeon, YH, Brodaty, H, & Chesterson, J (2004) Respite care for caregivers and people with severe mental illness: literature review. *Journal of Advanced Nursing* **49**(3), 297-306.

Who uses respite?

- Of primary carers who use respite:
    - 63% care for 40+ hours per week
    - 48% care for someone aged 65+ years
    - 42% care for a parent
    - 32% care for someone with a mental or behavioural condition (which includes those with an intellectual or developmental disability and autism).
    - 40% don't have a fall back informal carer to assist them.

- 15.8% (121,700) of all primary carers identify an unmet need for respite.
- 72% of primary carers who have an unmet need for respite require it on short notice or an irregular basis.

Source: Australian Bureau of Statistics, 2012 Survey of Disability, Ageing and Carers

- The draft Service Concept also highlights the lack of evidence to demonstrate the effectiveness of respite. However much of this research has sought to establish whether respite is a proven 'solution' for a range of issues including delaying entry into residential care or reducing carer burden. While respite may achieve these outcomes for some carers, for many it's simply an opportunity to have a break. Respite isn't designed to radically change the ongoing circumstances of a caring family. It simply provides what many other Australians get to experience every weekend, or when they take annual leave. As with a holiday, the outcome might simply be that the carer can cope a little better for a time, or that they have an opportunity to spend quality time with their children or with other family members and friends. The outcome might be that the interactions between an adult child and their elderly parent are less strained, or that their relationship is in fact strengthened by the opportunity to spend some time apart.

- It's therefore important that any future service model which aims to shift to an outcomes-based approach applies an appropriate and sensitive measure of the impact of respite.

- As raised previously in this submission, the Network also has concerns about access to planned respite being restricted to the multi-component intervention, and strongly believes that this support must also be available as a stand-alone service.

- The Network supports the acknowledgement in the draft Service Concept that there will need to be a direct pathway for emergency respite support which is separate from the multi-component intervention.

- We also note that there is an absence of reference to carer retreats within the draft Service Concept's discussion about respite. While the more conventional forms of respite are identified on page 17 of the Discussion Paper (residential, day centres and in-home respite), retreats offer carers an opportunity to get away from the caring role and the home environment for several days.

Q21: 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?

- Access to a consumer directed approach for respite will be advantageous for some carers. Depending on the level of choice and control afforded to the carer, it may provide far greater flexibility to identify and implement innovative solutions to meet their individual needs. See previous comments on the advantages and disadvantages of CDC for carers and the key considerations.

- However, a CDC approach won't be preferable for all carers, and in fact the provision of block funding for respite can still enable organisations to provide innovative and flexible solutions; see service examples below. A future Integrated Carer Support Service model should therefore include a mix of funding options.

SERVICE EXAMPLES: Carers NT Flexible Respite options in the Northern Territory

Troopy program: Carers NT offers respite programs which enable carers to take a break while the people they care for are accommodated in a modified troop carrier ('troopy') which travels from community to community under the supervision of a community-based service provider. Benefits include that:

- Each community can use the Troopy to suit the needs of the carers on their own community.
- Carers NT supplies the Troopy, camping and picnic gear, trailer, fuel, camera and some food for outings
- The local service provider is responsible for the safe and responsible use of the Troopy vehicle while it is in the community.

Mobile overnight respite camp: Remote respite camp program is offered for periods of up to a fortnight at a time. This enables carers, families and care recipients with dementia to take a break. Carers NT provide the transport and staff to provide meals, personal care and culturally appropriate activities. Benefits include that:

- Care recipients don't need to be sent away from their community.
- The camp is held in a culturally appropriate location.
- Daily activities are determined by the clients.
- The camp is coordinated and delivered by the Carers NT Remote Respite Team who have many years' experience in relating to and working with Indigenous families in the Top End.
- All equipment and supplies are provided, including camping and picnic gear, camera, trailer, fuel and food.

Counselling

Q22: Much of the evidence relating to effective counselling programmes for carers is focused on CBT. What other 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?

- In line with our previous comments on information, education and peer support, the key to effective counselling provision will be providing a range of options to suit the individual needs of carers. While online and telephone counselling may be preferable for carers who are unable to leave the home or who are located in a rural or remote area, there will be many other carers who will only access face-to-face counselling. The choice should be up to the carer.

- Counselling currently offered by the Network includes face-to-face, individual and group, family, telephone, email and skype counselling services. While some Associations employ their own counsellors, others have a network of contracted/brokered counsellors which cover metropolitan and rural regions and can provide bilingual and culturally sensitive services in some areas.

Contractors include experienced social workers, psychologists and counsellors with carer and condition specific expertise.

- A few examples of the range of counselling services offered by the Network include:

  - Carers Tasmania: Grief counselling
  - Carers ACT: In-house counsellors including a trauma and mental health specialist and carer specialist.
  - Carers NSW: as well as in-house counsellors in Sydney, Coffs Harbour and Tweed Heads, Carers NSW also offers carer sensitivity training for its brokered counsellors to ensure they are knowledgeable of the specific issues that carers face. Carers NSW also offers 'Talk-Link', a six week group counselling program run over the telephone. Specific Talk-Link groups include those for carers of someone who has suffered from a stroke, Motor Neurone Disease, dementia and 'Wellbeing and Mindfulness for Male Carers'.
  - Carers NT: Family therapy, play therapy and 'sandtray' therapy. Carers NT also has a registered Music Therapist who provides services to carers and those they care for. Each program is individualised and the Music Therapist works closely with those involved to determine the direction and specific goals of the therapy.
  - Carers SA: Brokers 30 counsellors who are trained in understanding carers. Carers SA delivers the training, conducts ongoing evaluation and regular updates. The counsellors deliver counselling to carers across South Australia, with a specific focus on rural and remote areas.
  - Carers WA: Bereavement counselling and support groups, dementia and challenging behaviour support groups, young carers counselling, couples counselling, family counselling.

- Collaborative research undertaken by Deakin University and Carers Australia has demonstrated that carer-focused counselling utilising a range of theoretical frameworks and delivered under the National Carer Counselling Programme is effective in improving the personal wellbeing of carers both immediately and for some time after completing an average of 6 carer counselling sessions. Initially piloted by Carers Victoria in 2010, and later incorporating Carers SA and Carers NT, the longitudinal study was designed to evaluate changes in carer subjective wellbeing at three measurement time points: (a) prior to commencing the program to establish a baseline of subjective wellbeing, (b) immediately after completing the six session counselling program, and (c) three months after the counselling sessions ended. The results demonstrated that the carer-focused counselling intervention effectively increased the overall subjective wellbeing and satisfaction of carers with individual life domains. Crucially, this gain, induced by the counselling sessions, did not diminish over the three month period following the final counselling session.[8]

- A variety of counselling approaches and techniques should therefore be available in the future Integrated Carer Support Service to meet the individual needs of all carers. While CBT may be the most effective counselling approach for some carers, it may not be appropriate for all groups, particularly Aboriginal and Torres Strait Islander carers. It will also be important to have counsellors and staff who are skilled, experienced and knowledgeable in working with specific cohorts of carers, e.g. young carers, CALD carers, Aboriginal and Torres Strait Islander carers.

- A range of counselling techniques will also be particularly important when providing support to young carers. For example, training recently provided to counsellors through Carers Australia on the needs of young carers of people with mental illness included Acceptance & Commitment Therapy and strengths based practice as well as CBT.

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[8] Cummins, RA, Hammond, TG, & Campbell, P (2014) Carers Counselling Intervention Study', Volume 4, Australian Centre on Quality of Life, Deakin University