

## NSW COMMUNITY CARE FORUM

(PO Box 3124 Rhodes NSW 2138)

This submission represents the views of members of **NSW Community Care Forum (CCF)**, as a part of its ongoing input to the development of carer supports and the reforms to aged care and disability generally.

The CCF plays a key role in sector support. It brings together a range of non-government stakeholder representatives working in community and sector development involved with in-home and community-based supports for older people, people with disability and their carers. Members include regional Sector Support & Development Officers, state-wide policy and development officers, non-government industry bodies and consumer peaks. The CCF meets six times per year to pool information, identify issues, monitor and respond to policies in order to provide information to service providers and consumers through the membership networks of participating organisations and engage with and provide advice and information to key decision and policy-makers in the following areas:

- Policy, planning, access and developments for older people, people with disability and their carers;
- Consultation structures and processes;
- Information strategies to promote and improve access;
- The allocation of resources for, and within, relevant programs;
- The relationship between program areas and government jurisdictions.

Aged and Community Services NSW and ACT provides the secretariat support for the Forum.

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The CCF appreciates the opportunity to comment, and particularly acknowledges the contribution of the Sector Support Development projects across NSW and the local service provider interagencies that gave input through these projects

This submission is written as a collation of members' views in response to the specific questions posed in the consultation paper, *Designing the New Integrated Support Service*, which reflect several key messages.

### **KEY MESSAGES**

In every relevant situation, the carer must be acknowledged as a part of the life of the person they care for. The presence of a carer and the nature of their role should always be part of the initial assessment of a person with disability or older person, and documented to ensure their continued participation. For instance, with the consent of the person they care for, a carer must be provided with information, inclusion in discussions and with physical space alongside the person they care for in the health system. Likewise, awareness of carers must extend to the places they may not necessarily present together, but the relationship and its responsibilities become relevant for the carer, such as at school or work. An integrated carer support service must acknowledge and relate to the other components of the carer's personal life, including health, family, friendships, and the ongoing context of the caring role.

CCF acknowledges the shift to a consumer focus which is occurring in both aged care and disability reforms, and supports the immense benefits of individualised funding, particularly the entitlement system that will be available to eligible people with disability under the NDIS. The latter will undoubtedly offer to reduce the physical responsibilities for carers in those situations. However, we are concerned that:

- both reforms emphasise creating new systems, which fail to understand the strengths of the existing infrastructure and collaborations that support individual outcomes, especially at a local level;
- neither reform places the integral relationship between individual and carer appropriately in person-centred planning by allocating a component of the support package to supporting the carer as a partner in care;
- the role of case management has been grossly underestimated for people with chronic and complex health care needs both in aged care and the disability sector;
- information about the changes has not been targeted to carers, despite their assumed role in providing so-called 'informal care'; and
- self-management of supports and/or funding under CDC and NDIS will potentially create a new burden for carers.

CCF agrees that the unique needs of the carer must also be addressed separately from those of the person being cared for through an integrated carer support service. It is a well-known fact that carers tend to focus on the person they are caring for, and not favour themselves when allocating resources [page 47]. This may account for some of the

difficulties of finding evidence matching carers' requests to research on outcomes, to which the paper alludes [page 18]. We do not believe, however, that it is acceptable to design a system with the presumption that many carers will miss out on supports. Nor do we believe that the allocation of support based on 'highest level of need' [page 19] is appropriate, given the clear benefits of early intervention in preventing carer burnout.

CCF is pleased that the paper recognises individual choice and circumstances as determinants to caring [page 7]; willingness and ability have often been assumed in the past as natural products of a familial relationship. Indeed, reflecting the issues presented in the 'Statement of Need' section, we believe that any future Carer Needs Identification process should be used, not as a rationing tool, but to assist carer support practitioners to consider and respond without judgement to carers, knowing that:

- the caring role is complex and is not static;
- every relationship between carer and care recipient is different;
- for some, caring is a lifelong commitment;
- a carer or care recipient may opt out of the relationship at any time;
- effective carer supports must be appropriately targeted to the individuals involved, with understanding of their personality, physical and intellectual abilities, stress levels, coping skills etc;
- individuals' need for carer support may be episodic and/or it can be coming for many years; and
- flexibility in both the manner (face to face, telephone, online etc) and timeliness (weekend, evening, middle of day day etc) of supports provided is essential.

CCF perceives that carers are fearful of these reforms and losing their current carer supports. Unfortunately, there is extreme frustration and cynicism amongst carers of older people and in the caring sector generally about what has happened in the rollout of My Aged Care, and the Carers Gateway by extension. The apparent lack of communication strategies and delays in processing people to the point of service delivery [not simply call centre wait times] are regarded by many as obstacles deliberately put in place to control demand and save the government money. Going forward, an effective integrated carer support service must focus on the carer at the centre, not the system. It must recognise that a rigid gatekeeper model will stop many eligible carers from accessing preventative supports, resulting in widespread carer breakdown and crises, which ultimately prove costly for both families and the economy. The only option is engaging well with carers and their supporters from the start; otherwise, stories of negative experiences are shared amongst community members and added to existing fears, so that whole groups of people become disengaged. Current examples include:

- if the participant cannot be contacted after three visits, they have been removed from My Aged Care;
- if a phone assessment has taken place, it has not been accurate or followed through; and
- clients and carers are waiting 6 months or more for services to commence, with reports of respected Elders passing away while waiting for service.

CCF want to emphasise that cultural sensitivity is paramount to the design and delivery of accessible carer supports. The integrated carer support system must be informed by the learnings of the My Aged Care experience and must be guided by community advice in order to be inviting and appropriate for carers. A National Carers Gateway, like My Aged Care, should be only one of several 'soft options' for accessing information and referral pathways for carer support, and only a small component of resource allocation. Carer supports are most relevant and appropriate when delivered locally, by familiar people. Anecdotal evidence indicates that Aboriginal people and people from culturally diverse backgrounds, for instance, are not accessing My Aged Care and providers are not receiving the volume of referrals that they did prior to the introduction of the single access point. Aboriginal people prefer a personal 'yarn' [ie. face-to-face assessment] conducted by a trusted local Aboriginal provider, with whom they have developed a relationship based on the provider understanding their individual circumstances and mutual trust. Indeed, an Aboriginal carer may be the child or grandchild of a Stolen Generation Member, traumatised through past government policies, fearful of institutions where they spent their childhood and unlikely to provide intake information to an official 'Gateway'. It will be the same for many carers from countries that have experienced war and oppression.

CCF is also aware that this discussion paper is about the 'design' of the new integrated carer support service. Further discussion and planning is required on how these supports will be funded into the future. CCF would contend that it is imperative that program funding continues to support services for carers. Supports and services for Carers should not be reliant on individual funds provided to care recipients as part of their individual packages.

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## Questions in the discussion paper:

### OVERVIEW/AWARENESS [PG 22-24]

#### Preventative focus

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

- community education that normalises caring, combined with multiple carer support services spread across communities and a 'no wrong door' approach will create greater opportunities to identify carers and for them to feel comfortable to seek support
- one message from/about a 'one-stop-shop' is not going to succeed when carers do not recognise themselves as carers
- not 'one-size-fits-all', but diverse methods reflecting diversity among carers; for Aboriginal carers, for instance, the most effective and efficient means of raising awareness would be opportunities to connect locally through promotion of specific Multi-component Support Packages and Peer Support programs [see below]
- getting the message out that it is ok to ask for assistance/help via multiple channels: pamphlets at hospitals, doctors surgeries, social media (ie. Facebook)', social workers, outreach workers who go to schools, hospitals, nursing homes etc
- general community media should be used in order to create open conversation and understanding of carers: local newspapers and community radio stations
- staff and volunteers to understand the range of carer support services available and information provided to carers at initial and relevant times

#### Young carers

To what extent should awareness be raised through schools and how could this best be achieved in a cost effective manner?

- schools should both educate about carers and reach out to them, whether students, parents or teachers who have caring responsibilities; we need to create caring environments in schools to encourage kids to express their feelings/emotions
- develop resource that can be utilised in schools or program that can be rolled out nationwide to increase understanding of issues and empathy
- an outreach worker to do an education series in schools about carers and how support can be accessed in the local community; this must not forcibly 'out' young carers before they are ready to self-identify, though
- remember that 'young carers' are under 25 years; also in after-school jobs, sports and other clubs, TAFE, university, work etc
- the diversity of caring roles for this group includes primary or secondary carers, for a parent, grandparent, sibling or partner/spouse
- quite often young carers are isolated because of their caring role and required to miss school to care, not only for primary care recipient but also other siblings
- younger onset dementia specifically impacts this group of carers
- Community Liaison Officers from Department of Education and Training should be on board; processes must be developed in consultation with the Education Department, Aboriginal Education Consultative Group (AECG), Aboriginal Education Officers (AEO), Aboriginal TAFE Coordinators and Aboriginal University Units to develop short term programs, identify young Aboriginal carers and the role they may be playing within their families
- innovative programs involving volunteers can work well with Y-gens; Anglicare's Young Carers Program, for instance, has been heavily supported by the University of Western Sydney (now Western Sydney University or WSU), linking WSU students with young carers to provide tutoring and peer support<sup>1</sup>

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

- people requiring care do not necessarily have a health situation; disability and ageing are not illnesses and caring occurs in all areas of life
- resources are best allocated to a universal community campaign, within and via all government institutions

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- we could reach young people by creating positive images through social media in a way that is relevant to these kids – use their language
- remember that it takes nothing to embarrass young people; it's hard for some teenagers to say "I am looking after my mother", so they need to be able to ring up anonymously, like young carers helpline as part of Carers NSW
- the communication strategy must be presented in a non-evasive way through school newsletters, as well as word of mouth, which is powerful to young people
- sometimes young carers are deliberately 'hidden'; parents fear their kids will be taken off them or the young carer does not want to ask for help and let the adult for whom they are a carer for to think they are not coping.
- young carers are a hidden cohort within Aboriginal Communities and often this role is shared by several members of the family; some young carers have come into the family unit through Out Of Home Care and/or foster care and then find themselves in the caring role of their grandparents, aunts and uncles

## INFORMATION PROVISION [PG 25-26]

### Are carer organisations today, as well as the Carer Gateway sufficient?

- the Carer Gateway is too generic and not much information is provided currently; many services are still not listed, due to delays with departmental changes to funding programs and contracts
- categories on the Carers Gateway data base and search function are not user-friendly; carers were accustomed to the Data Diction keywords on the Commonwealth Carelink website, so why not use that system?
- like My Aged Care, it does not reflect real-life questions people ask or how they need their information to be presented; carers are reporting that My Aged Care is not improving access to services, but multiple assessments and delays
- the Carer Gateway, like My Aged Care, is not always an appropriate pathway for Aboriginal people or people from CALD backgrounds, not everyone has the presumed resources or tools, and people who do not have the technology to access the Gateway and literacy and numeracy have not been taken into account
- the Carer Gateway needs to focus more on wellness and reablement
- anecdotally CCF understands that very few carers or referrers are using the Carer Gateway so not sure how effective it is in assisting carers
- one-stop-shop models have limited value; access depends on carers being proactive and it is difficult to tailor responses to individual needs from a central point, unless it is multi-locational and staffed with a very well-trained staff, who are multi-cultural, multi-disciplinary etc
- a national call centre is frustrating when they ask you how to spell the suburb in which you live; how do you build trust in their local knowledge and the accuracy of information they give you, if they cannot spell your suburb?
- too much of the national carer support funds are being spent on the Carer Gateway; it should have a smaller part of the pie
- websites are good for carers who want to remain anonymous and/or gather information at their own speed, perhaps while still coming to terms with a new situation or deciding if they want to accept a caring role; likewise, the distance of a phone call is preferable to a face-to-face conversation or giving an email or residential address
- carers should be able to access information from/about local carer support services without having to commit; brochure stands in community places, such as libraries and shopping centres, and resources at expos are ideal for this
- there are many effective local carer support services that provide information and an ongoing community presence and a relationship of trust with carers; they are funded through the old HACC Program [now CHSP in aged care and NSW CCSP in disability], which are not detailed in Annex B<sup>2</sup> and have an uncertain future [see below] [ie. *GUIDING PRINCIPLE: Reuse of infrastructure*]
- a 'hub and spokes model would be the most effective way of utilising existing local knowledge, skills and experience of current carer support services [ie. *GUIDING PRINCIPLE: Retaining strengths of the current system*], with a hub/call centre in each state to create a consistent framework and links for common promotion and initial access, when needed; the hub should immediately refer to a local provider and not waste time on intake or assessment, especially when the caller is distressed [see below] [ie. *GUIDING PRINCIPLES: Simple & Nationally consistent, locally responsive*]
- it is insufficient to have a call centre in only one place, thereby limiting potential staff; the key access point for carer supports must be able to recruit appropriate bilingual and bicultural workers to meet specific communities' needs [ie. *GUIDING PRINCIPLE: Equity of access*]
- the majority of Aboriginal Carers will rely on an Aboriginal provider they have developed a relationship with, not necessarily a specific carer support organisation, but an Aboriginal person/worker or provider that they know, one who understands their individual circumstances and can assist them; a Stolen Generation Member may not want the Carer to disclose information to someone they do not know or trust
- the information provided needs to be culturally appropriate, easy to read and enticing for Aboriginal people [eg. have Aboriginal art and Aboriginal people promoting supports]
- some carers might use an APP for phone focussed on local area services

<sup>2</sup> The description of current programs [Annex B] does not mention Alzheimers Australia's Key Worker Program either

## Would individualised recommendations be of benefit when carers are undertaking or receiving other services [specific to situations]?

- yes, providing names and numbers and saying 'call Mary and tell her "Dragana gave me your number"' is more personal and effective than 'this is the brochure, call this number'; it's about real people, and carers feel greater confidence to call when details are on a local level and concrete [ie. GUIDING PRINCIPLE: Carer focus]
- there are many effective local carer support services that other services without specialist knowledge rely on and refer to; in Sutherland Shire, for instance, these are Sutherland Shire Carer Support Service, St George/Sutherland Shire Dementia Advisory Service, St George/Sutherland Shire Dementia Carer Support Service, a multicultural provider and an Aboriginal provider [ie. GUIDING PRINCIPLE: Recognisable to both carers and local service networks]
- local carer support services have developed in response to the specific circumstances of carers in their communities, including language, culture, local schools with disability units, specialist health centres etc; when carers are time-poor and stressed, location and contextual supports are often the difference between someone accessing support and not [ie. GUIDING PRINCIPLE: Address current and emerging carer needs]
- Sutherland Shire Carer Support Service is a standalone organisation that has developed a hands-on model of responsive, local supports for carers as their sole focus over the past 20 years; the Design Concept would benefit from a close look at their operations, which are very different from peaks and other large, regional providers [ie. GUIDING PRINCIPLE: Innovative, tailored and flexible supports]
- individualised recommendations are crucial to receive other services; one size does not fill all, and personal circumstance varies from client to client
- carer support should wrap support around a person; at least an individual plan facilitated by a local service provider and case management of complex carer needs with other involved service providers
- Aboriginal people prefer holistic approaches; therefore individual information provision must be tailored to a carer's individual needs.

## INTAKE [PG 27]

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

- the purpose of intake must be clearly and respectfully explained upfront, so the carer understands what is going to be asked of him/her and how this information will be used; a time-poor, stressed carer may need to choose another day for that process in order for it to be viable
- different methods suit different people and circumstances; some find telephone calls very intimidating, rushed, not giving the real picture and face-to-face intake works the best, whether home visits, office environment or in a local café
- not using too much technical jargon; let carers select their own language
- staff responsible for intake must be excellent listeners, clear communicators and have the sensitivity to respond appropriately to carers who are distressed; they must also have knowledge of service options and the context of carers' needs in order to facilitate quick and effective matching
- the frontline service providing the first contact families have with carer support is so important; this can be/have been very intimidating
- it can't be assumed that the carer does not want to re-tell their story; good carer support focuses on the carer at all times, not simply data collection
- when carers do not want to re-tell their story, data should be available for re-use with consent; for instance, linking My Aged Care records of recipients with the carers'
- the new system should respect and value external 'supporters' and recognise that often the initial 'fact finding' for a time poor or distressed carer is a friend or neighbour; it's good that the Carers Gateway do not require invasive registration, like My Aged Care
- there is always someone in the Aboriginal community that is a key person or a support service or organisation in the area that is aware of the complexities and dynamics of the families in the area; sadly, quite often these people and services are used as a last resort, instead of a first point of call when intervention could have been implemented

### When should intake be a mandatory process? eg. to what extent would intake be required to facilitate access to peer support or education [ie. limit its utilisation]?

- this depends on the nature of the supports being given; arranging for an individual to receive a home visit or to attend a group obviously has some WHS implications, which should be discussed openly with the carer
- carers must be able to make informed choices about their involvement in service design; some will simply accept generic support or education, especially in the beginning when they are unsure of their role, their needs or what is possible, and forcing input could be a disincentive to further support



- a basic ‘yarn’, at least, needs to occur when there is a young carer involved or the client’s needs are substantially higher than carer is able to provide safely; for instance, in Aboriginal culture, it is culturally inappropriate for a young male carer to be showering his mother or female family member, and vice versa
- intake must always be about giving the carer information and opportunities; it needs to be done to ensure support accessed is relevant for carers and a good use of their time

## EDUCATION [PG 28-29]

### How can we encourage [time poor] carers to access education support?

- accessing education should not be seen as a failure, but as a normal part of caring; the availability of education reflects the seriousness of caring and community regard for carers
- provide topics they want: NDIS explained, Wellness forums around self-care, how to transition to aged care residential or other alternative care, computer classes, first aid
- carers themselves are the best way to promote the benefits of improved knowledge, confidence and skills, not to mention the social, fun side of interacting with peers through group education
- it must be easy to access education, whether online or in person, with clear, accurate information about content and no onerous registration processes to pose disincentives
- time-poor carers need a good reason to attend – topic/speaker/peer support/food/fun; combination and variety is important
- formal education sessions have to be facilitated by trained people, not volunteers; also resources available (ie. interpreters) or facilitators who have appropriate language skills
- on all occasions when face-to-face education is advertised, respite must be offered to enable some carers to attend; and/or respite in the home or other locations so that person can participate without interruption
- in-home training by allied health specialists or nurse educators is the best option for carers who need education to use new equipment or perform complex personal care tasks or wound management for the person they care for
- education support for young carers should be age-appropriate (ie. delivered in a ‘fun’ way and preferably with peers) and held in familiar venues close to public transport
- in the Aboriginal culture, face-to-face is more appropriate than other forms of support, and an Aboriginal carer would prefer the education and training program were delivered by an Aboriginal person if possible
- current collaborations within the CHSP/CCSP Sector Support and Development networks have produced very effective workshops through knowledge of carer issues, involvement with services through the care recipient, sharing information about education and supports available and flexibility around the time of the workshop; organisers know that carers may be late or not attend if things change, and demonstrate empathy and support around this<sup>3</sup>:
  - **Example:** *‘Meaningful Engagement in Activities for People with Dementia’ workshop facilitated by Alzheimer’s on the STARS training calendar in Marrickville. The training was promoted to carers by the Dementia Advisor and organisations in the local area; many carers registered to attend. STARS contracted Alzheimers Australia to facilitate two workshops on the same topic; the one in the morning was tailored for carers (a more suitable time) and staff and volunteers attended the afternoon workshop. Carers have also attended many other training workshops (Mental Health First Aid, looking after our mental wellbeing, dementia, responding to behaviours of concern), as they are promoted locally and held in an area close to home which makes it easier for the carer to attend.*

### How can we encourage carers to participate and complete an [cost effective and efficient] online education programme?

- making the program easy and interactive to allow for different levels of literacy and learning styles
- this can’t be the only option; not every carer has access to internet or has the language/capacity to do online training
- social isolation is a problem for carers; online methods should not be used if they threaten to reinforce that separateness
- to encourage participation and completion of online programs, carers could be provided with computer facilities and/or social supports, such as ‘study buddies’
- group education works the best, as carers tend to learn more from each other; also the shared experience adds value and reduces isolation
- provide information to all local services who are a point of contact with carers
- utilising computer facilities already in the community to provide adequate accessible technology or appropriate place where the technology can be accessed eg. Council libraries and schools

<sup>3</sup> Under HACC, the target group was always both the care recipient and the carer, and there is strength in expanding this model of education through Sector Support Development Training, which is statewide and in local areas in NSW.

## 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?

- local carer support services are best placed to promote available education and encourage uptake, but their staff are unlikely to champion external training without firsthand experience or testimonials from carers or trusted colleagues
- carer support practitioners should be valued and utilised in the development and delivery of education to ensure relevance when being directed to carers
- when sessions are out-of-area, local carer support workers could accompany individual carers or match peers to attend together
- by ways of promoting outside of the normal avenues, such as with religious groups, community hubs, local schools, media advertisements: television, newspapers, magazines
- community announcements on local TV stations, the ABC, ITV and SBS; also YouTube shorts
- possibly running educational groups and peer support groups along in conjunction with programs running for the client or formal care providers; carers access SSDN training services in local areas where training is relevant and suitable to their needs
- utilising 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
- education should work both ways; so-called 'professionals' can be educated too:  
*Example: Young Aboriginal mum of 24 is palliative. She is married with 3 children and lives in an isolated area. She and her family are still living quite traditionally in many aspects, with extended family nearby to assist with caring. Part of her treatment involved traditional medicines collected and made by her father. This young girl wanted to partake in traditional medicine as well as modern medicine, but because she missed two appointments with oncology, she was removed from the treatment list. The Aboriginal case management service assisted in the education and information sharing for the health staff around traditional medicine and the importance of traditional medicine being part of her treatment, not instead of. They were resistant at first, but the perseverance of the case managers in education and coordination with oncology allowed for the best possible outcome. The staff stated that they found this invaluable, and now have a new appreciation of Aboriginal Culture. Again Case Management was a vital component of this process; it encouraged and allowed education and information sharing to flow in both directions.*
- educate My Aged Care staff on what a carer is; for instance, family member living overseas is not an informal carer
- targeted education to mainstream community groups and services at a local level on supports available and avenues to access these supports; this should include clear directions on where and how to get help when there are significant barriers to access (eg. language, immediate threat to safety, transport, no immediate access to internet or phone etc)

## PEER SUPPORT [PG 30]

### 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?

- the paper assumes guest speakers are costly; this is incorrect, as most appear free of charge
- paid workers are essential for creating and sustaining a well-organised support group; carers are fine peer educators and occasional supports for each other, but it's not fair or realistic to expect them to take up another ongoing role (ie. coordinating and organising), in addition to their caring one
- good groups don't run themselves, particularly when members are time-poor and experience additional disadvantages of language, cultural, social isolation etc; successful groups require specific skills, leadership and energy, and it can take months or years to establish a reputation amongst carers and referrers [and attract those free guest speakers]
- funding is required to support these groups; use of space, refreshments, marketing, formal training within the group model can be costly eg. manual handling
- a web-based community page where peer support organisers can advertise their activities themselves, with no special IT skills required, just straightforward listing; the site should provide the option to upload photos and flyers, if desired<sup>4</sup>
- a government-hosted but community-regulated linking service (like what some private radio stations do); this has risks and should have caveats/disclaimers, but is worth trying
- 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

<sup>4</sup> Eg. <http://www.sscsi.org.au/calendar-of-local-events>

- web-based methods may include a Carer Support blog, social media to prompt discussion [eg. Twitter or a closed Facebook group, so carers can talk to people in same situation and feel free to express themselves with some anonymity]
- weekend getaway for carers to allow them to 'declutter' and be more open to support

### How can a peer support model be designed which encourage carers to participate and remain engaged?

- carers can invest in a model that promotes group problem-solving, in which they feel valued and can assist others, especially new carers
- carer-led and -designed models are optimal, but funding must be easily available to support them; carers should be paid for their expertise
- community group transport could be accessed to transport carers who are isolated
- support groups that are involved in systemic advocacy or co-design of programs are not for everyone, but some carers find them empowering and a brief and productive distraction from their personal situation
- 'storming, norming and performing' takes time to develop (ie. retreats, conferences, weekends away)
- Engagement Officer to re-engage with carers and keep them connected

### Should peer support be a service able to be accessed without pre-conditions or structure processes [as a start for specific groups]?

- support groups are essential as the entry point to ongoing carer supports, allowing carers to attend when they wish, as caring allows or when topics are relevant; an informal support group allows time and space for a new carer to develop trust before talking to peers and/or workers about his/her situation and consider more intensive services, such as education for themselves or even respite attendances by the person they care for
- many carers would prefer to meet informally to "see what's going on", prior to committing to specific groups

## NEEDS IDENTIFICATION & PLANNING [PG 31-32]

### To what extent should goal based planning be used at the assessment stage of the process?

- the new system must offer a 'soft entry' option for assessment for those who are new to the role and/or uncomfortable with providing their personal details or participating in an assessment process
- assessment is not a one off; it needs to be continuing evaluation of needs, as they are changing all the time
- a carer's health and well-being is an essential part of a specialist carer assessment; the carer must be the focus and properly listened to, just as the person they care for is, under person-centred assessment processes
- goals and plans work for some carers but not for all; it needs to be an individual, person-centred approach, as there is no 'magic' formula that works for everyone
- some carers only want help to plan for specific events, such as emergencies, evacuation and disasters, or if they become ill and unable to care; this, together with financial and legal planning, provides confidence and peace-of-mind
- culturally-appropriate case management (Aboriginal, CALD and mainstream) takes care of this when families have been supported for significant amounts of time; needs identification is an important part of care planning which is done in consultation with the care recipient and or carers of that person
- perhaps model it after the NDIS model, where the *First Plan* is not so much about goal-setting, but about putting in place the "necessary and reasonable supports" that are needed right now, without overwhelming carers with everything new; succeeding plans can progress to goal-setting, as desired by the person
- to give a person direction as to where they are going and accountability with the local organisation; use SMART as the process

### Would a goal based planning approach be worthwhile [if not in conjunction with a funded package or financial allocation]?

- often carers are so stressed and overwhelmed at the assessment stage that goal setting is out of the question; is this a good use of their time anyway?
- goal based planning should be available to people at different stages for instance, for young carers who need help in thinking about their future as soon as practicable (which they're unable to do much when they're swamped in their caring role) and when their caring role ends
- 'Consumer Directed' means the person has something to direct, and it is clearly worth the investment of their time; without a package for the carer, there is no guarantee and no parameters in which to plan
- in NSW, much has been done to educate people with disability about 'goals' and goal-setting through My Choice Matters and other pre-NDIS projects, much less in aged care; carers would need the same, but would it be cost-effective?



- perhaps goal-based planning is not cost-effective under limited funding in the carer support program, but surely, an assessor can ensure that the person is already linked to other services – career counselling, employment/training agencies, volunteer tutoring services; this is already happening under the Young Carers Program at Carers NSW

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

- the system cannot rely on this, especially if it requires pro-action; carers should have choice
- it sounds like another cost-saver, and could compromise the system if not used appropriately; some carers are able to self-assess, others not, for various reasons
- it recognises that people are their own best experts on themselves; however, self-assessment is part of the process which should also include possible other evidence-based assessments to assist those who are still on the journey to self-awareness
- it could be used as a part of the continuous evaluation of a carer's changing needs, but requires careful design to remove jargon and ensure sensitivity, language and culture appropriateness etc; carer support practitioners would need training in how to 'read' it and link it back to service delivery
- online tools assume computer literacy, web access etc; will the assessment be translated into community languages?

## A MULTI-COMPONENT INTERVENTION [PG 33-41]

### General

How can we ensure these supports are allocated to those carers who will benefit the most from them [to apply preventative thinking]?

- clear articulation of the benefits of preventative supports and provision at a local level should assist more carers to access carer supports before crisis situations, which then require costly interventions, including hospitalisations, centre based respite etc
- a self-assessment at this point could facilitate increased carer choice; what we see in the current system is carers being referred for support, when My Aged Care or the care recipient's service provider may see the benefit, but the carer may be in a different frame of mind and when contacted they don't identify themselves as needing support after all
- how do we determine who will benefit most when carers are often hidden, isolated and not very good at expressing their needs?
- establishing rapport and a relationship of trust is the essential first step, drawing on case management service and /or organisations that have been previously supporting the family [this is inclusive of all cultures]; through care planning, all of the multi component interventions would be identified in consultation with family and carer

### What should be the criteria by which this is determined?

- assessment for preventative carer support must focus on risk factors likely to contribute to carer breakdown and inability to continue with the caring role, such as carer depression, injury or ill-health through lack of self-care, complex and multiple caring roles and insufficient formal supports for the care recipient
- carers of people who are not in receipt of formal supports are particularly at risk; the NDIS should provide all that is needed to support those with disability, but the aged care system will continue to have limited supply and the burden of filling the gap will fall to carers
- isolation is one of the most significant factors identified in regional and remote areas
- carers at financial disadvantage must be prioritised

### 1. Multi-component Support: Financial Support

How can we help carers to use these funds appropriately [for themselves] without large administrative burdens on carers or providers who may be assisting them?

- carers already fear having to manage their loved one's care like a small business under NDIS; few carers are interested in managing another allocation and therefore the burden would outweigh any benefits
- CDC and NDIS have provisions for others to pay invoices etc; this is a necessary part of individualised funding
- individualised funding systems require complex and costly administration; likewise, voucher systems are messy and require detailed processes around unspent funds etc
- funding for individual carers must not occur at the expense of group supports; the system should help as many carers as possible, and allow easy entry and exit as individuals wish
- some carers need an individualised support funding package to facilitate their role as carers (that includes transport)

- there is concern that carers would use any funds they receive on behalf of care recipient rather than themselves
- where individual funding occurs, CCF recommend a cap on the cost of administration, as the cost will vary from provider to provider, and for remote Aboriginal carers the costings could be higher due to isolated areas

## 2. **Multi-component Support: Carer Mentoring**

When would a coaching programme be most effective for a carer [ie. carers' needs vary over time]?

- as early as possible in their caring role / in crisis situations / transition out of the caring role
- when the carer identifies it is needed or a client's needs require more attention that the carer is able to provide

Should this be a mandatory part of the service or should mentors should be able to determine whether the carer has the capacity to forgo coaching until another time [ie. for carers preferring only intermittent contact]?

- nothing in a carer support service should be mandatory; carers should always have choice not to accept help as part of their assessment
- 'mentor' is a big word; local carer support service staff are very good at providing support to carers who want intermittent contact and occasional advice by phone, email or in person
- BaptistCare run a good mentoring/coaching model for new carers of people with dementia; it utilises volunteers whose caring role has ended and is very cost-effective
- the Lifecircle volunteer program supporting carers of people dying at home also works well

## 3. **Multi-component Support: Respite support service**

Will moving to more of a consumer directed model, where funding is attributed to an individual carer, result in unintended effects?

What might these effects be and how can they be mitigated?

- a specific allocation for respite as an add-on to NDIS and CDC/aged care packages would be viable; it could be managed alongside the care recipient's funds and allow the carer to plan ahead with confidence, rather than depending on wait lists [but what about unfunded care recipients?]
- if funding is allocated without parameters, most carers will use the funding for the care recipient, as they sometimes do not see the benefit or the dollar value of carer support/counselling/group support for themselves; indeed, a carer may not use the funding as required and may prefer to forfeit services to save for something of higher value such as an orthopaedic mattress or self-recliner chair

## COUNSELLING [PG 42-43]

What other counselling programmes and techniques would be beneficial in reducing carer burden [vs online or phone]?

- it is important for carers to offload, de-brief and explore their feelings; 'counselling' should be recognised as a normal aspect of health and well-being and language used to avoid negative connotations associated with access, such as shame
- telephone counselling through Carers NSW is working well; please don't waste resources on a new tender process and endanger current infrastructure, including staff who need job security
- online or by phone, scheduled sessions can provide regular checking in and ensuring carers are linked with the local, community based services who are available when needed
- bereavement counselling is vital for carers who have lost their caring role or if caring has changed due to the institutionalisation or death of the person they care for
- it would not be considered appropriate to deliver counselling programmes through media or online to Aboriginal people; it is more culturally appropriate for carers and recipients to gather as a group, depending on the situation, or on an individual basis, and face-to-face
- other suggestions are: Wellness/Meditation/Mindfulness; Art Therapy; Dance Therapy; music therapy
- retreats and weekends provide an environment of respite, when carers can be 'free' to focus on self-care

Could these be delivered to a broader group of carers through telephone or online channels?

- this doesn't have to be centralised; depending on carer preferences and service willingness to engage carers outside their local geographic target group, local providers could add their times and topics into a pool to be advertised through the state hub, just as Carers NSW now promote local carer support groups, training and other events

- can the health system help with this cost through Medicare and private health insurance?
- maybe for young carers, but not for the older generation
- one-on-one support could be done online or telephone, but it cannot be exclusively online, unless in real-time Skype, as two-way interaction is important

## SPECIFIC CARERS [PG 44-47]

- **Young carers** [see above]
- **CALD carers** [in addition to comments above]
  - Existing community care program infrastructure embeds carer support in the local community organisations that are known and trusted access points for those seeking all types of assistance, where initial communication is culturally and linguistically appropriate; these providers also collaborate with specialist carer support services.
  - Access to culturally appropriate case management services is paramount. This can assist in the access, referral, coordination and carer support.
  - CALD providers report that in-home, non-emergency respite is not always seen as value-for-money in the community, as it is sometimes perceived as mere “babysitting”; respite workers who also perform domestic tasks, food preparation or exercise therapies while watching over the care recipient.
- **Aboriginal carers** [in addition to comments above]
  - The one-stop-shop is not a culturally appropriate access pathway for Aboriginal people. The service sector should be funded to guide both carer and client through the process.
  - Culturally appropriate resources should be made readily available through Aboriginal outlets, such as Aboriginal Medical Services (AMS), Aboriginal Health Liaison Officers (AHLO), Local Government Aboriginal Liaison Officers (council based), CHSP-funded Aboriginal Sector Support Development Officers (SSDOs), Aboriginal Ability Linkers (AALs), NSW Lands Council Network, Koori Mail, National Indigenous Radio Service, NITV, Central Australia Aboriginal Media Association (CAAMA).
  - The implementation of the My Aged Care has been extremely negative for Aboriginal people. The lack of understanding and willingness to participate from the RAS providers is less than acceptable.
  - Carers are often embarrassed or shamed because organisations of authority will look badly on them as they cannot look after themselves or other members of the family and then will have FACS involvement on the doorstep.
  - An Aboriginal Carer may be the carer of a Stolen Generation Member who was institutionalised from past government policies. The last place a Stolen Generation Member would want to live is in an institution like setting, such as residential 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
  - Aboriginal Carers may have a caring role for people who live in other geographical areas other than the local area, thus their support needs are different from non-Aboriginal carers.
  - As a rule of thumb, Aboriginal services have been operating in a person centred way for many years. Only in recent times has it been recognised by the government as a preferred model of care. The problem is the mainstream services often find it difficult to adjust to what the client wants, not what they are told they need. This is particularly evident where there is little or no choice of service providers.
  - There are families who have been supported by other organisations that are now asking to return to Aboriginal organisations because they are not satisfied with non-Aboriginal providers; lack of cultural understanding can have dire consequences:
 

**Example:** *An elderly woman presented at emergency feeling unwell. She was speaking tribal tongue and appeared to be delusional. The Mental Health Team was called, and the process of having this woman scheduled was implemented. A staff member called the Aboriginal Mental Health workers from the local AMS, who attended the hospital and recognised the woman as a Stolen Generation Member. The Aboriginal staff explained that this Elder felt she had been ‘caught’ (hence the tribal tongue). Her vitals were quite unstable; however, she was refusing treatment. The Aboriginal staff negotiated with hospital staff and it was agreed that her vitals would be closely monitored and scripted medication would be administered with assistance from the Aboriginal staff and a GP from the AMS for the next 24 hours. The woman was removed from the hospital and taken to her home. A medicine man from up river was called down to perform ceremony. The woman was then returned to the hospital willingly and accepted treatment willingly. The outcome was that the Elder was in renal failure, not psychosis as first diagnose, and did not need to be scheduled. Her beliefs were acknowledged and allowed and played a vital role to her treatment and recovery. The education was invaluable to the hospital staff.*
- **LGTBI carers**
  - People just want to be cared for as people, not put under a spotlight or have to ‘out’ themselves to be classified and treated differently. Every carer should be able to choose what information they give in order to

receive individualised support and their relationship with the care recipient is not the service provider's business.

- Aboriginal / CALD / LGBTI carers need a “safe-haven” to meet and participate in their caring role and to be provided an equitable service delivery depending on their needs and circumstances.
- **Regional, rural & remote** [in addition to comments above]
  - The National Carers Gateway is not ideal in rural and remote areas, as it primarily based on technology and that services are available and providers are willing to attend particular areas.
  - Multi-disciplinary workers go into isolated areas with limited resources to educate on supports other than carer focussed supports.
  - There are many isolated Aboriginal communities where phone and internet connection is non-existent and the literacy levels are quite low and lifestyle remains quite traditional.
  - In isolated areas it is cultural practice for the family to care for the Elders, so there is a domino effect for the young person in the area of schooling, employment, social inclusion etc.
  - In regional areas where there are often isolated communities, there is little or no choice of service provider. Some service providers will not provide service in some Aboriginal areas, the isolation or remoteness makes this not possible. The services could be brokered back to Aboriginal service providers, but there have been occasions when the response was [unhelpfully] “no, we have our own support staff”.
  - Concern that resources may not be sufficient in isolated areas.
- **Dementia/YOD** [see above]

## PROVIDING INTEGRATED SUPPORT [PG 48]

- **Assistance for the person they care for**
  - There is a need for carers and care recipient to access the community and to do fun things together eg. dementia ballroom dancing program, dementia cafes etc as well as to have a break from caring responsibilities
  - Aboriginal Carers would possibly be more engaged and willing to participate if the person they are caring for is included in the whole process. Respite care, so the carer can access groups, could be an issue therefore by including all parties you may engage more people.
  - Activities involving both the carer and care recipient have been very successful in providing community interaction, support and education [ie. **GUIDING PRINCIPLE: Cost effective**]; for instance, the Dementia Cafe model has been cost effective and successful support for the carer in an informal community based setting, as well as supporting the care recipient<sup>5</sup>:  
***Example:** A CHSP service has a social support group program (language specific) for the care recipient to attend. Carers provide transport and are known to the service provider and to other carers. Carer G has not identified and is not accessing carer supports. Service wants to offer a space at same time as care recipient program for the carers for education/support and require funds for the speakers and morning tea. This meets the needs of this particular group; it is also needs based, local and an organic response. Carers decide the program and self-direct and make use of time when the care recipient is supervised.*
- **Support to Access Employment / Working Carers**
  - Supports suggested in the paper are excellent examples of what a central hub could offer; networks and knowledge of the employment sector and the expertise of a carer-specific financial counsellor or career advisor is beyond the scope of most community-based carer support services.
  - Much has been said about how respite hours don't always coincide with working carers' working hours and present a disincentive to stay in the workforce. Some services address this by extending transport time (eg. picking up a person at 8 am for a 10 am group Social Support, then dropping off a person at 5 pm after dropping off everyone else from 3 pm).
- **Support when caring changes or ends** [see also Counselling and Planning]
  - Carers of people with dementia need continuous support, especially through transitional stages (eg. moving to residential care facility) and beyond, as they need to reintegrate back into the community.
  - Carers also need support at the end of the caring as their life can change completely at that time - loss of role, identity tied up in being a carer, isolation and need for support to reengage with community.
  - Aboriginal Carers may require additional support during “Sorry Business”. This might include returning an Aboriginal person to Country and costs associated with “Sorry Business”.

<sup>5</sup> recent changes to CHSP have resulted in changes to program eligibility - the care recipient is now the client, not the carer.