Submission to the Royal Commission into Aged Care Quality and Safety:
Consultation Paper 1 - Program Design in Aged Care

January 2020

AN AUSTRALIA THAT VALUES AND SUPPORTS ALL CARERS

ABOUT CARERS AUSTRALIA

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

Carers Australia welcomes the opportunity to provide input into *Consultation Paper 1 – Program Design in Aged Care*. We acknowledge that program design will play a key role in creating a new aged care system that is person centric, accessible, promotes autonomy and recognises the need for addressing issues of equity, diversity, future infrastructure and workforce requirements.

We are not in a position to address all the questions posed and have focused on those where we have more familiarity with the issues.

RESPONSE TO DESIGN QUESTIONS

1. What are your views on the principles for a new system, set out on page 4 of this paper?

Carers Australia fully supports the principles for a new system as outlined in the Consultation Paper, noting that some of these principles will need to be more clearly defined or teased out to determine what they mean in practice. We are particularly pleased to note that the principles include supporting older peoples' informal care relationships and connections to community.

2. How could we ensure that any redesign of the aged care system makes it simpler for older people to find and receive the care and supports that they need?

- ***How could face-to-face services most benefit those older people at the entry point to aged care (or when changing programs)? What should those services include? Who should they be directed to? Where should they be located and who should provide them?***

Carers Australia recognises that significant efforts have been made to address issues with the My Aged Care portal. However, we note that IT remains a challenge for many older Australian who are unfamiliar with or unable to use new technologies.

Answers to the questions above should be informed by the outcomes of the Aged Care System Navigator Trials.

Carers Australia understands that the System Navigator Trials, include a mix of formal information hubs, community hubs for peer support and specialist support workers for vulnerable people. The idea of the system navigator project is supportive of the principle that older Australians who are identified as being part of a special needs group and their family and friend carers need different access points to the aged care system which offer connection, familiarity and trust. We support in principle the use of dedicated care coordinators or case managers (similar to NDIS), noting that it is hard to evaluate the effectiveness of NDIA Local Area Coordinators because they have been diverted to planning activities.

We agree that peer support and inclusive societies promote positive ageing, and the System Navigator Trials designed to support older Australians in maintaining their individual autonomy.

Community hubs under the pilot which provide outreach services and group and individual support are an excellent way to maintain community connections and be engaged in current and emerging services and supports. Specialist support workers, who can meet in informal local community spaces such as libraries and community centres, present the opportunity to bridge the isolation that special needs groups often report facing when accessing government services.

3. Entry-level support stream

People maintain their homes and gardens, do laundry, cook meals, get themselves to appointments and attend social engagements across their whole adult lives—some people may choose to pay others to do these things—but mostly they handle them with little assistance. As people age and need support with everyday living activities, how should Government support people to meet these domestic and social needs?

- ***Should these supports be made available to everyone (or just those that cannot purchase assistance)?***

In the interests of providing a sustainable aged care system, Carers Australia favours the principle of equity over equality. Subsidised supports should be made available to those who are more financially disadvantaged and less capable of supporting their needs.

- ***Are there some supports that need increased funding? Are there new or innovative approaches that should be recommended for inclusion in this stream?***

We note that the Consultation Paper includes assistive technologies amongst important entry level supports. The capacity of assistive technologies, in all their diversity, to significantly transform the lives of aged people and their carers across ageing processes, is phenomenal.

Some assistive technologies, including those involving home modifications, can be purchased through Home Care Packages, although cost is likely to be a factor even with respect to level 4 packages where the consumer also needs to cover the costs of other services.

However, even when people begin to experience the impacts of ageing on their mobility, strength, endurance and some deterioration in sensory perception, but are not in need of high levels of assistance and care, assistive technologies can make a significant contribution to their quality of life and help to mitigate further functional deterioration. Some examples might be as basic as orthotic support, light weight/long handle equipment, jar openers, hand rails, apps which assist with prompting in relation to medication management, contrast strips, sensor lighting and personal alarms. Many people will be able to afford this kind of assistance but others, especially if they are reliant on pensions, will struggle – particularly if they need a combination of these aids.

The current Commonwealth Home Support Programme (CHSP) cap of $500 per year to finance a range of assistive technology supports (and sometimes service them) in many cases will not stretch far enough. And, of course, older people need to know what technologies can help them and how they can access them, and may require training in how to use more complex technologies.

The National Aged Care Alliance (NACA) published an excellent, comprehensive Position Paper on Assistive Technologies for Older Australians in 2018 which we would hope will provide guidance to any aged care reforms in relation to assistive technologies.[1] The benefits of early intervention and bundling services is explored in the paper and the cost/benefits of offering assistive technology compared to the provision of personal assistance is explored.

4. Investment stream

The benefits from regular and planned respite, reablement and restorative care are well documented, but the services are in short supply. What incentives, including additional funding, could be introduced to encourage providers to offer greater and more flexible options, including major home modifications and assistive technologies, which meet the needs of the older person, carer and caring relationship?

The provision of respite under the current system is of particular concern to Carers Australia. While the allocation of respite places in residential aged care is provided under the ACAR model, there is no requirement for providers to use their allocation, and it is clear that supply is not meeting demand for what may be described as genuine respite, i.e., the opportunity for family and friend carers to take a short break from caring or for aged people to take a break from self-care when they require it.

While there are other options than a stay in residential care for providing respite, there will be a continuing requirement to provide the residential option, especially when the person needing care has high and clinically complex care needs.

As noted in in the Aged Care Financing Authority's (ACFA) 2018 Report on respite for aged care recipients, the administrative difficulties associated with managing respite allocations can be a real disincentive for providers who will not be subsidised if they exceed their allocation.[2] This, along with the comparatively low level of subsidies and supplements for respite care compared to permanent care, provides another reason why providers may not be willing to offer respite care. One of the conclusions of the ACFA report is that the market should be able to respond to consumer demand. Recommendation 12 of the report is that:

> If neutrality in the funding of respite and permanent residential care is achieved, the Government should remove the minimum and maximum allocation rules for respite care and allow providers to respond to consumer demand for respite, subject to appropriate transitional arrangements and monitoring of the impacts of such as change on respite availability.[3]

Another funding change, which might encourage providers to make respite more readily available, would be to receive a special administrative fee to compensate for the additional costs of bringing in

[1] https://naca.asn.au/wp-content/uploads/2018/11/NACA_Assistive_Technology_for_Older_Australians_Position_Paper-1-June-2018.pdf
[2] https://www.ndis.gov.au/understanding/supports-funded-ndis/reasonable-and-necessary-supports
[3] https://agedcare.health.gov.au/sites/default/files/documents/11_2018/acfa_report_on_respite_care_for_aged_care_recipients.pdf

a new resident, similar to that which has been proposed for permanent residents in the AN-ACC model.

Having said all that, residential respite is generally not the preferred option either for carers or the people they care for. It has a great many drawbacks. These include:

- Many places are booked months in advance, while in other places respite cannot be booked far enough ahead and for the times it is needed (for example, so carers can plan and book holidays).
- Residential aged care facilities usually impose minimum stay periods, which does not suit many carers, who may need, or prefer, to have shorter and more frequent breaks.
- Moving to an institutional environment can be a very alien and disconcerting experience.
- Delays in ACAT assessments mean that carers are often unable to access respite when they need it.

Paid replacement care in the home is a much less disruptive option, but expensive if paid for out of packages - if it is required for a more than a few hours a week or a few days - and unaffordable for those on lower level packages unless the consumer can cover the costs.

One form of out-of-home respite, which is particularly favoured, is dedicated respite accommodation offering day and overnight care in a more home-like environment than residential care. This type of respite can be used for both planned and emergency care. The facility may be stand-alone or may be attached to day care facilities.
Advantages are:

- The older person may use the day care facilities, with occasional overnight stays, so are in familiar surroundings with people they know. This can be particularly important for people with dementia.
- Overnight stays are in a house or homelike environment, rather than an aged care facility, so it is more normalised than residential respite in an aged care facility and may even feel like a holiday for the consumer.
- Cottages offer dedicated short-term stays, so there is a known number of beds, and respite clients are not competing with people and providers using short-term residential accommodation as a prelude to entering permanent residence.
- There is greater flexibility, and can suit carers who prefer to have one- or two-nights respite more regularly, rather than blocks of respite, or can be used in combination with blocks of care. For example, a carer may have a two-week holiday once a year and a night or two break in other months.

The problem is that there are comparatively few such facilities available. According to the aforementioned ACFA Report, there were just under 100 providers of cottage respite in Australia in 2007-18. The ACFA recommendations included recognition that “cottage respite is in effect another type of short-term residential respite care, when considering neutrality of funding settings following the RUCS study, consideration be given to whether the current funding model for cottage respite is appropriate”.

Hammondcare, in its 2019 Pre-Budget Submission noted that there had been no additional Commonwealth funding for cottage respite in over a decade.[4] They advocated an expansion of block funding agreements through grants of up to $1 million, depending on the hours and days of support offered, to expand the number of these facilities. They also noted that there are no capital grants available to providers of these services and suggested that government could also provide dedicated capital grants or zero interest loans to expand the number of services available. This funding could be used to support the purchase of land and construction or capital upgrades and renovations for rental properties for these purposes.

5. Care stream

As people's needs increase and go beyond what can be managed with entry-level support or with their carer, they may need care services—personal care, as well as nursing and allied health. What are the advantages and disadvantages of developing a care stream, independent of setting?

- ***Is the concept of 'reasonable and necessary' as used in the National Disability Insurance Scheme applicable to the level of support that could be funded under this stream?***

It depends what part of the concept of "reasonable and necessary" you have in mind.

As explained on the NDIA website, in order to be considered reasonable and necessary, a support or service:

- Must be related to a participant's disability.
- Must not include day-to-day living costs not related to your disability support needs.
- Should represent value for money.
- Must be likely to be effective and work for the participant.
- Should consider support given to you by other government services, your family, carers, networks and the community.[5]

The requirement to consider support which is or would normally be provided by families and family and friend carers has been particularly problematic. As expressed in the National Disability Insurance Act 2013: "A participant's reasonable and necessary supports take into account any informal supports already available to the individual (informal arrangements that are part of family life or natural connections with friends and community services) as well as other formal supports, such as health and education". The rather vague concept of what it is reasonable to expect for families and "other natural connections" to do has led to the rejection of services requested by participants or their representative for inclusion in plans and it has infringed consumer choice.

Carers Australia has recommended that, at the very least, sub-section 34 of the Act be revised to read:

[4] https://treasury.gov.au/sites/default/files/2019-03/360985-HammondCare.pdf
[5] https://www.ndis.gov.au/understanding/supports-funded-ndis/reasonable-and-necessary-supports

what it is reasonable to expect families, carers and informal networks to provide taking into account the complexity, intensity and duration of that support, its impact on family functioning and the sustainability of informal caring relationship.[6]

To the best of our knowledge, aged care services are free of any support and service constraints based on expectations of the nature of support that families and friends should provide and we believe it should remain that way. While there might be certain social norms about what parents should do for their children, there are no universal Australian norms around what family members should do for the aged (as opposed to norms and rules around what they shouldn't do).

- ***What are the advantages and disadvantages of block funding, providing cash or a 'debit' card with a fixed annual budget to older people or a mixed model (combining block funding with other approaches) for this stream?***

Carers Australia strongly supports the principle of consumer directed service provision. The more decision-making power and influence that is put into the hands of consumers, the more providers will be required to respect their needs and preferences – providing of course that consumers have a real choice when they need to access services. Consumers and those assisting them to exercise choice, such as family members, must have the right amount of information and understanding to make good choices. Information must be provided in a way that is accessible and easy to understand by aged people and those who care for them, regardless of their level of education, ethnicity, cultural background or disabilities that can impede communication.

Having said that, we are well aware that that in thin markets, the promise of consumer choice can be hollow. We are familiar with the experiences of smaller disability support providers with insufficient upfront capital to support their fixed costs, liabilities and workforces and to absorb delays in payments when individualised funding replaced block funding under the National Disability Insurance Scheme (NDIS). A number of service areas with a small, dispersed consumer base had to withdraw from the market, not only leaving NDIS package holders with no effective choice when it came to purchasing approved supports, but sometimes with the loss of pre-existing services.

In such circumstances the restoration of block funding has its appeal, even if it does theoretically compromise the principle of consumer choice for some aged care consumers. While we are aware that viability supplements are available in residential aged care and home care, we are unclear about the extent to which these supplements preserve service offerings in thin markets and the extent to which they need to be expanded and adjusted to meet costs in different circumstances.

We are also aware that some service providers offer "debit cards" to recipients of home care packages which they can use to purchase eligible supports from the provider at their own discretion. We have not looked at the issues associated with this practice in detail, but can see no real in principle problem with it especially if it enhances consumer autonomy and saves in administrative costs. However, we note that such self-direction requires the investment of time, energy and organisational skills on the part of the package recipient or their families or representatives.

[6] https://www.carersaustralia.com.au/storage/carers-australia-submission-to-ndis-act-review-and-participant-service-guarantee-discussion-paper.pdf

6. Specialist and in reach services

How could the aged care and health systems work together to deliver care which better meets the complex health needs of older people, including dementia care as well as palliative and end of life care? What are the best models for these forms of care?

- ***What would be required to support in reach of multidisciplinary health teams from the health system in the care of older people with high needs? What other services could be used (24/7 on-call services, embedded escalation to specialists, access to relevant ageing specialists, telehealth or other technological advances)?***

The use of geriatricians within residential care and the wider community should be considered as a priority area because of their ability to manage the complex health needs of older people, including pharmacology, dementia and rehabilitation. However, access to geriatricians is largely available only to people in major cities. The Department of Health identified in 2016 that there were 619 practising geriatricians in Australia, with 87.6 per cent located in major cities.[7] The same report also reported that geriatricians are themselves an ageing workforce; with the average age being 48 years. Those intending to retire within the next 10 years were identified as 29.2 per cent. Given that geriatricians manage complex health issues and promote healthy ageing, increasing older Australians' access to geriatricians in a hospital outpatient, community health, nursing home or private clinical setting can prevent unnecessary hospitalisations and provide better health outcomes.

Residential aged care facilities should employ pharmacists on contract, either onsite or remotely, who are independent of the company that prepares medication for residents. The role of these pharmacists would be to conduct comprehensive medicine reviews to ensure that medication charts are correct and to identify any issues with polypharmacy. We note that 56 per cent of all reported care transition medication errors result from preventable adverse drug events.[8] An independent pharmacist check would assist to reduce communication errors and issues surrounding polypharmacy, and staff education and clinical intervention could be undertaken in a timely and efficient manner.[9] For example, the Wicking Dementia Research Education Centre RedUSE trial, which ran from 2014 – 2016 in 150 residential aged care facilities, involved pharmacists undertaking reviews of patients' Webster packs and undertaking one hour education sessions with nursing home staff over a six month intervention. The trial saw a significant reduction in the prescription of antipsychotics and benzodiazapine.[10] There is also benefit in adding a pharmacy review at the point of transfer from hospital to residential care or from the community to residential care.[11]

Nurse Practitioners provide valuable connections between medical practitioners, allied health professionals, aged care staff and consumers because of their ability to break down language and provide prescriptions, order scans and spend more time with patients. Under some models of

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[7] https://hwd.health.gov.au/webapi/customer/documents/factsheets/2016/Geriatric%20medicine.pdf

[8] McDerby, N., Kosari S. et al (2019). "Residential care pharmacists: another hole plugged in the Swiss cheese". *Journal of Pharmacy Practice and Research.* The Society of Hospital Pharmacists of Australia. Vol 49. pp 84.

[9] https://www.australianageingagenda.com.au/2018/12/13/on-site-pharmacist-a-first-for-aged-care/

[10] Westbury, J., Gee, P. et al (2018). "RedUSE: reducing antipsychotic and benzodiazepine prescribing in residential aged care facilities". *Medical Journal of Australia*. 2018. Vol 208 (9). pp 398-403.

[11] Op Cit (2019)

practice, they provide palliative care assistance, dementia support and can play a crucial role in hospital avoidance strategies.[12] Nurse Practitioners can be embedded within aged care facilities, hospitals, mobile clinics and private practice. However, numbers of Nurse Practitioners are low, with the Australian Nursing and Midwifery Board reporting 1,904 endorsed registrations in September 2019.[137] With Nurse Practitioners providing longer consultations, more follow up and reduced hospitalisation there is a real need to push not only for the training of more Nurse Practitioners but also for attracting and retaining them in rural and remote areas.[14] Carers Australia supports the Collaborative Care model where Nurse Practitioners work in teams with general practitioners and/or specialists.

Residential aged care facilities are required by law to provide residents requiring palliative care access to a qualified palliative care team, the establishment of an individual program to monitor and manage side effects, and is required under the AQSAS to ensure that the "comfort and dignity of terminally ill care recipients is maintained".[15] Approved Providers are responsible for providing access to a qualified practitioner from a palliative care team, and the establishment of a palliative care program including monitoring and managing any side effects for any resident that needs it. In addition, under Schedule 2 of Aged Care Quality Accreditation Standards, an Approved Provider is responsible for ensuring the comfort and dignity of terminally ill care recipients are maintained. We know from the Royal Commission into Aged Care and Quality and Safety that palliative care is an important feature of the health system, and that demand for palliative care will increase as our society ages in the coming decades. In addition to legislative safeguards, it is imperative that the community engages in broader discussions about living with a life limiting illness, death and dying with dignity.[16] To achieve this Carers Australia supports the recommendations made by Palliative Care Australia in its October 2019 submission to the Royal Commission on Aged Care Quality and Safety. With regards to dementia-specific palliative care, greater recognition is required by doctors, nursing and personal care staff, of the signs of pain in people with dementia and co-morbid conditions.

Wellbeing for older Australians also needs to be addressed by greater use of psychologists within facilities to help residents cope with depression, anxiety and loneliness. Research shows that psychology practices can help with the transition to residential care, grief and bereavement for loss of independence, loss of family engagement, dementia symptoms, and can reduce levels of staff stress and reduce the number of GP visits.[17] There is also a need for dedicated support for special needs groups, those consumers undergoing palliative care, those who have been subject to elder abuse[18], people living with dementia, Aboriginal and Torres Strait Islanders, CALD people, LGBTIQ

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[12] Dwyer, T, Craswell, A et al (2017). "Evaluation of an aged care nurse practitioner service: quality of care within a residential aged care facility hospital avoidance service." *BMC Health Services Research*. Vol 17. pp 33

[13] https://www.nursingmidwiferyboard.gov.au/About/Statistics.aspx

[14] https://anmj.org.au/australia-must-invest-more-in-nurse-practitioners/

[15] https://www.aihw.gov.au/reports/palliative-care-services/palliative-care-services-in-australia/contents/palliative-care-in-residential-aged-care

[16] https://palliativecare.org.au/pca-submission-to-the-royal-commission-into-aged-care-quality-and-safety-october-2019

[17] Bhar, Sunil (December 2016). "Innovative psychological support in aged-care facilities: Preliminary research and future directions". *InPsych*. Australian Psychological Society. Vol 38, Issue 6

[18] Leading Aged Services Australia (July 2019). *Improved access to psychological services in residential aged care: LASA Members Observations*. pp 9

people and survivors of institutional abuse. Although rates of anxiety and depression are lower than in younger cohorts, addressing the psychological health of older Australians should be a priority for ageing well policies. Within the wider community, efforts should be made to normalise psychology and healthy ageing practices. The onset of depression in older people has been identified by the as being caused by "disability, newly diagnosed medical illness, poor health status, poor self-perceived health, prior depression and bereavement"[19]. The National Mental Health Strategy, which is a commitment by Australian governments to improve the life of people with a mental illness and, where possible, to prevent the development of a mental illness and protect the rights of people with mental illness (including the right to access treatment and the restriction of chemical restraints)[20] is inconsistent in its application because it is state-based and services are skewed towards metropolitan areas. There is an urgent need for mental health and aged care services to acknowledge that mental health literacy and stigma are major barriers to older people accessing treatment.[21]

[19] Pachana, N (December 2016). "Facts on ageing: Demographic data is key for psychology to support the wellbeing of older Australians". *InPsych*. Australian Psychological Society Vol 38, Issue 6

[20] http://www.coaghealthcouncil.gov.au/Portals/0/Fifth%20National%20Mental%20Health%20and%20Suicide%20Prevention%20Plan.pdf

[21] https://aifs.gov.au/cfca/2019/02/13/normalising-mental-illness-older-adults-barrier-care