

## ROYAL COMMISSION INTO AGED CARE QUALITY AND SAFETY COUNSEL ASSISTING'S SUBMISSIONS ON PROGRAM REDESIGN

### PART 1 Overview

1. Commissioners Tracey and Briggs observed in their Interim Report:
 

It is clear that a fundamental overhaul of the design, objectives, regulation and funding of aged care in Australia is required.<sup>1</sup>
2. In these submissions, Counsel Assisting outline our current proposals for far-reaching changes in aged care program design.
3. In doing so, we acknowledge the complexity and dynamic nature of the aged care system, the potential for unintended consequences of reforms, and the need for careful consideration of interdependencies between program design and other aspects of aged care.
4. Aged care is an essential human service relied upon by over 1.3 million older Australians,<sup>2</sup> many of whom have complex needs and are highly vulnerable. It is imperative that continuity of services be maintained while reforms are implemented. Although the reforms are urgently needed, adequate time must be allowed for key factors in the system to plan for and transition to a clearly defined set of outcomes.
5. The proposals for change in these submissions envisage a new, redesigned aged care program, but these proposals cannot all be implemented overnight. A transition strategy would be needed, aspects of which may be implemented in the short term but some of which would involve staged implementation over the medium to longer term. It is possible that some aspects of the reforms we propose would require analysis of impacts in the course of a staged implementation. If duly implemented, we consider that the changes will lead to significant improvements in the ways in which aged care is subsidised and provided to the older Australians who need it.
6. The purpose of outlining our current proposals for a redesigned aged care program in these submissions is to elicit responses from organisations and entities involved in the aged care system, government, experts, users of aged care services and the general public, in order to build on the consultations that have already occurred.
7. These submissions follow, and have been heavily influenced by, a consultation process which commenced on 6 December 2019 with the publication of *Consultation Paper 1, Aged Care Program Redesign: services for the future*. In response to a general invitation for submissions on the proposals in that paper, the Office of the Royal Commission received 183

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<sup>1</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1, p 10.

<sup>2</sup> Department of Health (Cth), *2018-2019 Report on the Operation of the Aged Care Act 1997*, 2019, p 11.

- submissions from a range of labour and professional organisations, consumer groups, aged care sector peaks, providers, and government, as well as aged care experts and the public at large. Submissions, other than private submissions, have now been published on the Royal Commission website.
8. In December 2019 and January 2020, a number of consultations took place on the subject-matter of Consultation Paper 1 between staff of the Royal Commission and representatives of interested organisations, government and experts. Two days of large-scale consultations between staff and about 40 participants took place on 3 and 4 February 2020 in Canberra. The Royal Commissioners then held a hearing in the form of a workshop in Adelaide on 10 and 11 February 2020 at which a number of such witnesses gave evidence.
  9. During the consultation process and at the hearing on 10 and 11 February, some aspects of Consultation Paper 1 attracted general support. However, others were critiqued on cogent and compelling grounds.
  10. In light of what staff have learned through the consultation process and the hearing, Counsel Assisting now propose a new program design for aged care in this country which builds on, but differs in several material ways, from the proposal in Consultation Paper 1.
  11. In these submissions Counsel Assisting are not proposing that the structure of the program be arranged into an entry-level support stream, care stream and investment stream; or that care stream funding be agnostic of setting and capable of unbundling in a residential care context; or that care plans and individualised budgets be generated through the process of independent assessment for eligibility for funding.
  12. These submissions are not our final recommendations to the Royal Commissioners about program design. The Royal Commissioners invite further public submissions in response to these submissions. Counsel Assisting intend to give careful consideration to any such submissions in formulating final submissions on recommendations about program redesign and other aspects of reform of the aged care system.
  13. Our current proposal for program redesign includes the following noteworthy changes, each of which is important in its own way, and which in combination would achieve a fundamental overhaul of the aged care system.

**a. Needs-based entitlement to aged care**

Support and care in accordance with the assessed needs of each older Australian should become an entitlement based on need. People assessed as having needs justifying higher level care at home should not have to wait until a rationed package becomes available. People receiving care whether at home or in a residential facility should have confidence that their provider is funded to provide the care necessary to

meet their assessed needs. Such a move to needs-based entitlement should happen in two ways.

- **Linking funding levels to actual costs:** The first way in which care in accordance with assessed need should become an entitlement is that, for the first time, aged care funding would reflect the actual cost of providing care. Funding would be set by an independent authority on the basis of efficient standardised costs ascertained on regular intervals by the authority. Funding would be updated regularly. There would be scope for variation in subsidies based on differences in efficient standardised costs between places (for example, in remote locations) and taking account the needs of the people in certain recognised diverse needs groups receiving support and care. Providers of care would be required to account for their expenditure on care.
- **Uncapping supply of funding packages and places:** The second way in which care in accordance with assessed need should become an entitlement is that, subject to a cautious implementation strategy, rationing of aged care funding should be removed. Rationing is the process by which a constraint is imposed on the number of people who (even if assessed as needing aged care) are eligible to receive subsidised aged care. An orderly transition to the removal of rationing is required for a range of reasons, and the removal of rationing may have to occur at different times depending on regional conditions. The factors that must be considered in designing a transition strategy for uncapping supply on funding packages and places include:
  - Robust quality assurance about the entities eligible to receive uncapped funding must be in place in advance
  - Robust arrangements for ensuring accountability for expenditure of funding on care must be in place in advance
  - A reliable understanding of demand is needed for budgeting and planning purposes
  - Based on a reliable understanding of demand, and also of supply-side constraints, arrangements to avoid bottlenecks and inequitable access to services are needed in advance
  - Uncapping should be in line with the availability of supply-side resources such as growth in the necessary workforce.

b. **Reorientation toward wellbeing and independence**

People should be entitled to care that is not only of high clinical quality but also designed to enhance their well-being and quality of life. It ought also to respect the older person's preferences within the context of the relationships they have with their informal carer, partner or close family,

and their relationship with care staff, and their care provider organisation. Comprehensive assessments (establishing eligibility for funding) and care planning should be conducted in light of this objective. This, together with funding matched to assessed need and accountability for expenditure on care, would help to drive a shift in the system from rushed, task-based care, to high quality relationship-based care supported by funding for higher levels of skilled staff. The redesigned aged care program should have an increased focus on preventative and early interventions with the aims of maintaining and restoring function, sustaining independence, and enhancing wellbeing, in the best interests of each person receiving support and care. Care planning should reflect a person's choices, goals and strengths, not just their traditionally defined, objective, care needs. Care planning should prioritise quality of life from the outset all the way through to palliative care. It should encompass psychosocial supports and happiness, and should integrate with existing supports in the community, including from family, friends and support groups. Funding for supports to enable social connection should be available at all stages of aged care.

**c. Access, care finding and case management**

People should be presented with a much easier path to obtaining the information and the aged care they need. The new aged care program should make it easier for people to understand their options in order for them to make informed choices about, and to gain access to, the services they require. This could be achieved by presenting people with many pathways to aged care via referral from their existing contact points (such as GPs), and a seamless process involving care finding and assessment under a single banner to minimise confusion, in addition to the existing website and call centre. Whether the banner for the care finding/assessing functions should be 'My Aged Care' is an issue for further consideration, but our preliminary proposal is that it should be different. There should be performance rating information about different services to assist users to weigh their options. The process should involve personalised help, including face-to-face assistance from the outset for anyone who wants or needs it, as well as ongoing case management. The new structure under which this service would be provided will involve a new organisation and a new workforce. The new workforce of 'care finders' should be trained to perform these functions on a local basis throughout Australia, and they should be able to share local knowledge with people they are assisting and give advice about different care options. Care finders could arrange basic supports on an immediate interim basis and arrange comprehensive assessments. The institutional arrangements we propose for care finders and assessment are outlined later in these submissions. They should harness existing experienced expertise and resources wherever possible.

**d. Innovative accommodation**

The new aged care program should provide incentives for innovative accommodation options driven by choice, particularly directed at enabling people to remain in their own home or in forms of accommodation less institutionalised than full-time large-scale residential care. This may involve assistive technologies. This is particularly significant in the area of apparent demand for flexible and innovative supported accommodation in which more complex and intensive home support and care can be provided.

**e. Data collection and analytics**

Data analytics have the potential to improve the quality and safety of care provided to each individual. This is most obvious in areas such as in medication management and enabling preventative interventions where clinical data raises an early warning sign that a deterioration may be occurring. The new aged care program should be underpinned by standardised data collection. The data regime should be designed to take full advantage of available information communications technology, and to minimise administrative burden in the collection of the data. It should enable evaluation over appropriate time-frames of the performance of the new aged care program at the levels of the individual, the provider and the system overall, including its interfaces with the health system and other human services. Proper evaluation at the provider and system level is critical to effective improvement.

**f. Local strategies**

People should have equitable access to aged care irrespective of where they live and their background. There is insufficient data about areas of unmet need across the country. The new aged care program should involve strategies to improve coverage and equity of access formed or influenced at the regional and local levels wherever possible. This is needed because of profound regional variability in the depth of markets and other operating conditions. More must be done to take advantage of community-based co-operative support networks in rural and remote areas, and similar networks and organisations where diverse needs are concerned. Local government, community and diverse needs groups should be included in forming and influencing local strategies. The care finder/assessment organisation and the care finder network it manages has an important role to play in this regard.

14. At the same time, we propose that a number of features of the way aged care is currently subsidised and provided can remain in place, including the following:

- a. aged care should continue to be primarily funded by government subsidies, though individuals would also continue to make substantial contributions to the cost of their care

- b. aged care would continue to be provided by a mix of private for-profit businesses, private not-for-profit entities, social and charitable enterprises, religious bodies and governments
  - c. aged care would continue to be provided through residential facilities and home support and care services, although there might be proportionately fewer people in residential facilities over time, and there should be growth in the proportion cared for at home or in the community or in more flexible forms of supported accommodation
  - d. residential aged care services should continue to be bundled (i.e., they will include a mix of health-related, personal care, accommodation and other services)
  - e. commissioning arrangements should continue to apply: (i.e., subsidised aged care services would only be delivered by providers which are officially contracted, licensed or approved in some way (or ways) to deliver it).
15. Without descending into detail in these submissions as to which institutions should perform them and precisely how they should be performed, it is necessary to identify the key functions needed for the effective operation of the aged care system:
- a. data collection, data analysis and system performance evaluation
  - b. policy development
  - c. eligibility assessment
  - d. funding
  - e. system 'stewardship' (or governance)
  - f. market governance (including incentivising innovation and ensuring the transparent flow of performance information)
  - g. management of interfaces between Australian and State/Territory governments and their roles and responsibilities relating to aged care
  - h. workforce development and labour supply management
  - i. commissioning of providers and/or services
  - j. establishing and sustaining institutional arrangements supporting the care recipients and their families (including consumer feedback, complaints and advocacy)
  - k. setting of quality and safety standards
  - l. regulation of quality and safety
  - m. price regulation and
  - n. supervision of reform implementation strategy.

16. These are all critical functions, and there are clear connections between our current program redesign proposals (outlined in these submissions) and the institutional arrangements that would be necessary to implement them. We invite submissions as to how these linkages are most effectively to be developed.
17. In responding to Consultation Paper 1 numerous organisations and individuals put forward their own proposals of a future program design. The following are examples of the themes of such proposed redesigns. These examples do not identify all the elements of the redesign proposal in each submission.
18. UnitingCare Australia made recommendations as to further principles for the aged care system.<sup>3</sup> They submit that the ‘concept of “aged care” unintentionally perpetuates ageist stereotypes, suggesting a program based on ‘identifying needs that cannot be met by the individual’.<sup>4</sup>
19. The Federation of Ethnic Communities’ Councils of Australia (**FECCA**) recommended that the aged care system adopt a bio-psychosocial approach and ‘develop an empowering ecosystem for older persons, carers and communities’.<sup>5</sup>
20. National Seniors Australia suggests a model that is incorporated into existing healthcare arrangements through care check-ups performed by a general practice commencing at the age of 75, if not earlier.<sup>6</sup>
21. Silver Chain recommends a ‘continuum of care approach that supports consumers to access appropriate and timely care to meet their health and wellbeing needs’.<sup>7</sup>
22. HammondCare proposes that aged care ‘should be characterised by relationships’ and ‘not be seen as a commodity’. HammondCare states that the new program must focus on compassion as well as choice.<sup>8</sup>
23. Some submissions proposed, albeit at a summary level, quite comprehensive designs with suggestions around the delivery systems or models required to support the proposed new programs.

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<sup>3</sup> Submission of UnitingCare Australia, Consultation Paper 1, AWF.660.00147.0001\_0001 at 0007.

<sup>4</sup> Submission of UnitingCare Australia, Consultation Paper 1, AWF.660.00147.0001\_0001 at 0011-0012.

<sup>5</sup> Submission of the Federation of Ethnic Communities’ Councils of Australia, Consultation Paper 1, AWF.660.00155.0001\_0001 at 0006-0007.

<sup>6</sup> Submission of National Seniors, Consultation Paper 1, AWF.660.00030.0001\_0001 at 0025-0027.

<sup>7</sup> Submission of Silver Chain, Consultation Paper 1, AWF.660.00095.0001\_0001 at 0008-0009.

<sup>8</sup> Submission of HammondCare, Consultation Paper 1, AWF.660.00055.0001\_0001 at 0003-0004.

24. For example, Professor Kathy Eagar, director of the Australian Health Services Research Institute at the University of Wollongong, has recently submitted an expanded version of her initial submission,<sup>9</sup> proposing four funding streams administered through 60 or so regional authorities, with centrally allocated grants from the Commonwealth Grants Commission to each authority. The four streams are intended to fund services addressing a progressive hierarchy of needs: age friendly community services, primary aged care services (basic home and social support for which no assessment is needed), secondary aged care services (more complex home care, subject to assessment) and tertiary aged care services (residential care). Professor Eagar has proposed funding via direct grants for the first two streams, a transition to casemix funding for secondary aged care services based on an AN-ACC-like methodology, and AN-ACC funding for tertiary aged care services.<sup>10</sup>
25. To take another example, Catholic Health Australia<sup>11</sup> endorsed aspects of the proposals in Consultation Paper 1 but with significant modifications and additions. Catholic Health Australia supported the introduction of face-to-face assistance and proposed, subject to budgetary considerations, a regional network of 'contact/information/case management/assessment' centres, urging the Royal Commission to learn from the operational shortcomings associated with the Local Area Co-ordinator arrangements in the NDIS exposed by Mr Tune in his recent report.<sup>12</sup> The submission advocated assignment to a funding level or package rather than generation of individualised budgets, pointing to the subjectivity of the 'reasonable and necessary criterion' and the potential for disputation and review requests. Catholic Health Australia advocated the need for separate funding mechanisms for residential care and home care for a range of compelling reasons, and provided a detailed alternative design.<sup>13</sup>
26. Although delivery models were the not the focus of Consultation Paper 1, and we are not advancing detailed proposals on this topic in these submissions, the staff of the Royal Commission will be exploring these issues with some of the people and entities who have made submissions of

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<sup>9</sup> Professor Kathy Eagar, Australian Health Services Research Institute, University of Wollongong, *National Aged Care Program Streams and Funding Models* (January 2020), AWF.660.00121.0001

<sup>10</sup> Professor Kathy Eagar, Australian Health Services Research Institute, University of Wollongong, *National Aged Care Program Streams and Funding Models* (March 2020), AWF.660.00183.0001.

<sup>11</sup> Submission of Catholic Health Australia, Consultation Paper 1, AWF.660.00040.0001 at 0006-0008; 0012-0016.

<sup>12</sup> D Tune PSM, *Review of the National Disability Insurance Scheme Act – removing red tape and implementing the NDIS service guarantee* (December 2019). This report identified a range of operational problems such as resourcing and delays, inconsistent application of the "reasonable and necessary" test applied in formulating support plans and individual budgets, and overburden from combined support planning and case management roles.

<sup>13</sup> Submission of Catholic Health Australia, Consultation Paper 1, AWF.660.00040.0001 at 0006-0008; 0012-0016.



this kind. We invite further submissions from the public about the institutional arrangements, market structures and delivery models best suited to the new program design outlined in these submissions, and about any required modifications needed to align with optimal institutional arrangements, structures and delivery models.

## **PART 2            Interdependent areas of inquiry**

27. Designing a new aged care system requires attention to be given to a number of interdependent areas of inquiry. Program design is just one element of the design of the overall system.<sup>14</sup> In the context of these submissions, an aged care 'program' refers to a group of criteria and arrangements for providing particular services to particular people supported by government subsidies. The notion of the aged care 'system' is far broader.<sup>15</sup> These submissions are confined to outlining our current proposals for program redesign.
28. At the same time as advancing the development of program redesign proposals, we are acutely conscious of the need to ensure coherence with ongoing work on all other elements of the system. Further, at the same time as attending to system design, it will be critical to identify what would be required to enable the design to be realised.
29. Closely interdependent areas of inquiry include:
- a. defining and measuring high quality care
  - b. public transparency of provider-related information (including performance ratings)
  - c. access for groups with diverse needs, including Aboriginal and Torres Strait Islander people
  - d. quality assurance in commissioning of providers, and different forms of commissioning
  - e. quality and safety regulation
  - f. workforce
  - g. research, technology and innovation
  - h. funding
  - i. financing options.
30. It is worthwhile expanding now in a little more detail on the connections between program design on the one hand, and workforce and funding on the other.

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<sup>14</sup> 'Program' is taken to mean Programs 6.1 (Information and Access) and 6.2 (Services) in the Portfolio Budget Statements. 'System' is taken to mean all programs and linked programs for Outcome 6 in the Portfolio Budget Statements, as well as the inputs, outputs and outcomes to Outcome 6 (for example, quality regulation, aged care providers, the aged care workforce, family and friends of older people, the administration of ageing and aged care by the Australian Government), Department of Health, *Portfolio Budget Statements 2019-20, Budget Related Paper No. 1.0, Health Portfolio*, 2019, p 115.

<sup>15</sup> See also definitional approach adopted by Department of Health, *Portfolio Budget Statements 2019-20, Budget Related Paper No. 1.0, Health Portfolio*, 2019, p 115.

### **Workforce**

31. Specific recommendations focussing on workforce issues identified in the residential care context are set out in *Counsel Assisting's Submissions on Workforce* delivered on 21 February 2020.<sup>16</sup> Those recommendations include measures to raise the professionalism and ensure the stability of the workforce, including by developing better and more rewarding career pathways, introducing registration, making ongoing investments in training, and changes to terms and conditions of employment.
32. Our work is continuing in augmenting those proposals, and in particular addressing home care. As mentioned above in the context of transition and implementation, the development of the employed aged care workforce at all levels, and supply of appropriately trained care workers, nurses, allied health practitioners and clinical leaders, is critical to the success of the kinds of reforms which we expect the Royal Commissioners will in due course recommend to government.
33. Reflecting the need for much greater numbers of appropriately trained people to be involved in providing care, so too is there a pressing need for adequate funding that reflects the true efficient costs of providing high quality care. Estimates of those costs are largely built up from staffing cost inputs.

### **Funding**

34. It is clear that development and implementation of our recommendations will require greater levels of funding. However, merely providing greater levels of funding is not the only answer. Great care needs to be given to designing mechanisms that provide appropriate incentives for high quality care and impose appropriate accountability for the use of public funds. In a hearing to be conducted later in the year, the Royal Commissioners will hear evidence on a range of potential funding reform issues.
35. Without limiting the scope of the issues which will be addressed or prejudging the evidence, we outline below our preliminary proposals on the following funding issues which closely relate to program design:
  - a. Can a casemix model be applied outside a residential care setting and if so can it be applied both to basic home supports and also to home care?
  - b. Can and should a separate entitlement in kind or budget be conferred for respite and for education, counselling and other support services for informal carers?
  - c. How should funding for preventative, rehabilitative and restorative interventions, representing response to episodic deteriorations in a person's health, be separated from the person's level of funding for ongoing care?

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<sup>16</sup> Submissions of Counsel Assisting: Workforce, Adelaide Hearing 3, 21 February 2020, RCD.0012.0061.0001.

- d. Should a new casemix model such as the Australian National Aged Care Classification (**AN-ACC**)<sup>17</sup> be applied in the residential care setting?
- e. Should the levels of casemix funding be calculated consistently with the method for imposing casemix adjusted staff ratios recommended in *Counsel Assisting's submissions on Workforce* delivered on 21 February 2020?
- f. Should residential care casemix funding for ongoing needs be accompanied by an entitlement in kind or a budget for ongoing basic social supports?
- g. Should financial reporting of expenditure by care providers on the costs of care be required? If so, should adjustments be made to future payments in light of over-expenditure and under-expenditure (the process sometimes called acquittal)?
- h. What forms of funding should be employed in home settings? For example, for basic supports, should direct grants continue to be used, and in thin markets, should direct grants be used for both basic supports and more complex needs?
- i. Should the programs other than Commonwealth Home Support Programme (**CHSP**), Home Care Packages (**HCP**) programme and residential care programs continue as they are or are changes needed?

#### *Home support funding*

36. Currently, funding for basic domestic and social support including meals, some social engagement activities and transport, and some community-based care and nursing, is provided through the CHSP. Discrete grant agreements directly between government and providers fund provision of these services. People become eligible for these services via assessment through a Regional Assessment Service.
37. There are advantages in the CHSP funding model, because it provides more confidence about the expected funding stream (encouraging establishment and retention in areas of thin markets), and allows the flexibility to provide greater levels of service to people, and in places where they are needed.<sup>18</sup>

<sup>17</sup> The Department of Health is currently trialing a case-mix-based assessment and resource allocation model, AN-ACC, developed by a team led by Professor Kathy Eagar of the Australian Health Services Research Institute at the University of Wollongong as part of the Resource Utilisation Classification Study, commissioned by the Department since 2017: Eagar K, McNamee J, Gordon R et al., *The Australian National Aged Care Classification (AN-ACC). The Resource Utilisation and Classification Study: Report 1*, 2019, Australian Health Services Research Institute, University of Wollongong.

<sup>18</sup> Transcript, Mudgee Hearing, David Hallinan, 6 May 2019 at T6563.41-17. Transcript, Mudgee Hearing, Dr Rachel Winterton, 5 May 2019 at T6449.23-28. Transcript, Adelaide Workshop 1, Dr Gill Lewin, 11 February 2020 at T7772.42-47. Transcript, Adelaide Workshop 1, Professor Woods, 10 February 2020 at T7681.14-23.

- There may also be some savings in administrative costs by comparison with other forms of funding.<sup>19</sup>
38. However, there are also drawbacks. Block funding through grant rounds tends to confer an incumbency advantage, creating barriers to new entrants, and thereby potentially reducing competitive pressures on incumbents to innovate.<sup>20</sup> Further, funding through CHSP agreements is generally capped to a number of instances of service or in other words, limited outputs. It is often directed to attempting to meet the needs of people with higher levels of need than intended, particularly in light of the waiting lists for higher levels of home care via the HCP program.<sup>21</sup> Where this occurs, it is being deployed to fill gaps in another program and is not being expended to prevent deterioration, and maintain functioning and independence in the manner it is best designed to do.<sup>22</sup> Further, the CHSP is supporting those who cannot access more intense or complex care, and those needs are intended to be met by HCP upon assessment by an Aged Care Assessment Team (**ACAT**) or Aged Care Assessment Service (**ACAS**).<sup>23</sup>
  39. As we explain in detail below, we propose that a single comprehensive form of assessment should be available for each person. This assessment should be the pathway to eligibility in receiving whatever care the person needs from the spectrum of potential supports and care. There should not be a hard separation between basic supports and other care. We consider that on the available evidence this is the best way of assessing and meeting the needs of the person in a holistic way and in a manner most likely to prevent deteriorations, maintain function, sustain independence, and enhance wellbeing. At the same time, there may be advantages to retaining aspects of the funding approaches in CHSP for the provision of home support services. This will require local variation in funding approaches to ensure the appropriate range of services is available.
  40. It may be possible to devise and implement standardised levels of home care funding based assessment of need, just as this has been shown to be possible in residential care by the RUCS study.<sup>24</sup> Those funding levels should be set in a manner that reflects the true costs of providing the care. Independent assessment of each person's care needs would lead to

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<sup>19</sup> Transcript, Adelaide Workshop 1, Dr Henry Cutler, 11 February 2020 at T7754.8-16.

<sup>20</sup> See for example: Steven Bond-Smith. "*Discretely Innovating: The Effect of Barriers to Entry on Innovation and Growth*." Bankwest Curtin Economics Centre Working Paper 18/04, Perth: Curtin University.

<sup>21</sup> Exhibit 2-25, Adelaide Hearing 2, Statement of Clare Hargreaves, WIT.0071.0001.0001 at 0025 [118].

<sup>22</sup> Exhibit 7-1, Mildura Hearing, General Tender Bundle, tab 55, CTH.1000.0002.4038 at 4051-4052.

<sup>23</sup> Department of Health (Cth), *2018-2019 Report on the Operation of the Aged Care Act 1997*, 2019, p 25-25; 30.

<sup>24</sup> Eagar K, McNamee J, Gordon R et al., *The Australian National Aged Care Classification (AN-ACC). The Resource Utilisation and Classification Study: Report 1*, 2019, Australian Health Services Research Institute, University of Wollongong, p 2.

classification of the person to one of the particular standardised levels of funding. If it proves impractical to create standardised levels of funding for basic supports an option would be for the assessment to approve eligibility for certain volumes of such services to be provided in kind, or for a dollar-value entitlement for such services to be included in the person's home support and care package, based on an efficient price schedule for such categories of services set by the pricing authority.

*Carer supports and respite funding*

41. Supports for informal carers (including education and counselling) and respite should be the subject of specific assessment during the proposed comprehensive assessment process. Need for these supports should result in a dedicated component of the resulting budget, or an eligibility to receive those supports in kind. This would prevent the funding of these interventions being deducted from the older person's budget for ongoing support and care needs.

*Preventative, rehabilitative and restorative interventions funding*

42. Preventative, rehabilitative and restorative interventions, would not be funded from the individual's budget for ongoing care. Rather, these interventions should be available upon assessment on the basis that they represent a justifiable 'investment' of public funds, likely to delay or prevent the progression of the person receiving care to require higher levels of more costly ongoing care. We propose this should include episodic interventions needed to rehabilitate and restore functioning to a person following accidents and illnesses and home modifications and assistive technologies which pass a cost-benefit analysis, where the cost of the intervention is compared with the additional costs of care which would be incurred without the intervention.

*Residential care funding*

43. The current funding mechanism for determining funding levels payable to providers for care, the Aged Care Funding Instrument (**ACFI**), should be replaced by a more appropriate casemix-based model better reflecting the needs of higher acuity cohorts of residents and capable of being calibrated to reflect the efficient cost of high quality care for residents. In this regard, consideration must be given to the AN-ACC casemix system, which is currently being trialled.<sup>25</sup>
44. The new funding mechanism would involve the calculation of graduated levels of standard care funding based on the actual costs of providing care to residents in cohorts with similar care cost drivers, and should cover non-variable recurrent costs and adjustments for differential cost inputs arising from locality type, diverse needs and treatments for chronic conditions.

<sup>25</sup> Eagar K, McNamee J, Gordon R et al., *The Australian National Aged Care Classification (AN-ACC). The Resource Utilisation and Classification Study: Report 1*, 2019, Australian Health Services Research Institute, University of Wollongong.

45. The cost information on which the funding levels are based should be ascertained by an independent authority which would have cost monitoring and price setting responsibilities. There is an option for the authority to have an additional function of regional market evaluation, outlined in more detail below. An existing authority (such as the Independent Hospitals Pricing Authority) may have these functions conferred on it, or a special purpose authority may be established. The authority should establish a methodology for using actual cost data to set funding levels of the casemix classification hierarchy to reflect standardised costs of providing high quality residential care to the cohort of residents represented by each casemix classification, and for updating those levels from actual reported cost data at regular intervals.
46. Classification of an individual to a particular funding level should be the result of independent assessment by a comprehensive aged care assessment team.
47. In addition, the comprehensive assessment may include eligibility to receive funded social supports which enhance social connection and wellbeing, such as day activities, and transport to activities and appointments.
48. Eligible care recipients could, with the assistance of their care finder, select and enter into a contract with a residential care provider in their area. This provider would then receive all the residential care funding attributable to that person and may pool that funding (with the exception of the entitlement or budget for social supports) in order to provide operating funds.
49. The residential care provider should be required to ensure that all of the person's assessed needs are met and that the social supports for which the person is eligible are provided.
50. The residential care provider must co-ordinate the provision of all the individual's care and support holistically.
51. There should be no requirement to acquit, that is, to account to the funder for expenditure of the care funding on an individualised basis for each resident. However, in line with Recommendation 1 of *Counsel Assisting's Submissions on Workforce*,<sup>26</sup> it should be necessary for the provider to meet a casemix adjusted staffing ratio at facility level. We submit that regular financial reporting of care costs should be required, as a form of acquittal at the level of the particular aged care facility, this would create the potential for adjustments to apply in the next payment period in the event that providers have not spent the funding on care. This should be applied evenly to both over and under expenditure exceeding certain thresholds. Where a provider spends more on care in a payment period than paid to it in that period, it should be able to seek a reassessment of care needs of any residents for whom materially greater than assessed care was provided, to determine if

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<sup>26</sup> Submissions of Counsel Assisting: Workforce, Hearing 3, 21 February 2020, RCD.0012.0061.0001 at 0034.

the additional expenditure was reasonable and necessary. If the expenditure was reasonable and necessary in light of the reassessments, the provider should receive an adjustment covering the additional care costs in that period.

52. As part of financial reporting, payroll evidence should be submitted by providers to establish compliance with casemix based staffing ratios.
53. It would be illogical if providers were required to have staffing ratios in place for which the funding they receive is inadequate. Therefore casemix based standard funding levels ascertained and determined by the independent pricing authority must be consistent with the costs implied by the mandated casemix adjusted staffing ratios.
54. Whether overheads and return on capital should be included in casemix levels or be separately addressed is a matter for further inquiry at the forthcoming funding hearing.

#### *Means testing*

55. A logical regime of means tested co-contributions should apply in the redesigned aged care program. Staff of the Royal Commission are formulating options for proposals that will be examined during a hearing on funding and financing issues later this year.

#### ***Other programs***

56. There are also important special programs addressing the needs of some communities in regional, rural and remote areas (the Multi-Purpose Service Program - **MPS**) and Aboriginal and Torres Strait Islander people (currently covered by the National Aboriginal and Torres Strait Islander Flexible Aged Care Program (**NATSIFAC**) program and related programs). We recognise that it may be appropriate to accommodate the needs of these groups within the overall program redesign in a manner that involves special arrangements. This topic will be the subject of further attention later in the year.



## PART 3 Life planning

### **Proposals**

The Australian Government in cooperation with other levels of government should fund and support education and information strategies to improve public awareness of resources to assist people to plan for ageing and potential aged care needs.

These strategies should support a continuum of planning for ageing, including consideration of the limits of health care preferences for care, finances, housing and social engagement.

These strategies should support greater use of the Medicare Benefits Schedule-supported annual health assessment and bring people's general practitioners to the centre of their planning for ageing and aged care.

57. The Future Care Study 2018 surveyed more than 1,000 Australians and found that more than 75% have not taken any steps to ensure they receive the aged care services that they want.<sup>27</sup> Further, 46% of older people have not discussed their future care needs with anyone.<sup>28</sup>
58. Some barriers that prevent people from planning for their older age include: the sensitivities that underpin losing one's decision-making ability, legal costs, trust, family conflict, and having to hand over control of their finances.<sup>29</sup>
59. These barriers are accompanied by a broader community reluctance to discuss or plan for older age and subsequently for death. These can be very challenging conversations that require someone to engage with their own mortality and plan for worst case scenarios.
60. Why is it important that people plan? People's preferences for aged care are rarely articulated, and they are not supported by the open, systematic conversations that are needed to ensure effective care plans.<sup>30</sup>
61. Most people would prefer to age at home, but few adequately plan for this. A lack of preparedness or an unwillingness to plan for older age often means that when people do require aged care services, these decisions are not made until crisis point.<sup>31</sup>

<sup>27</sup> McCrindle, 'Future Care Study 2018', *Absolute Care & Health*, 2018, p 16.

<sup>28</sup> McCrindle, 'Future Care Study 2018', *Absolute Care & Health*, 2018, p 16.

<sup>29</sup> Submission of the Federation of Ethnic Communities Councils of Australia, Consultation Paper 1, AWF.660.00155.0001 at 0012.

<sup>30</sup> See for example: Transcript, Sydney Hearing, Professor Stephen MacFarlane, 15 May 2019 at 1755.1-9

<sup>31</sup> Submission of Dementia Australia, Consultation Paper 1, AWF.660.00162.0001 at 0009.

### **Low utilisation of advance care directives**

62. Reluctance to plan ahead is illustrated by the very low rates of utilisation of advanced care directives.<sup>32</sup> This may be explained by a lack of awareness and understanding about advance care planning in the community.<sup>33</sup>
63. Advance care planning ensures that care is delivered in accordance with a person's wishes. An advance care plan involves appointing a substitute decision maker and documenting a person's values, beliefs and preferences to provide clarity for health professionals who provide treatment and services.<sup>34</sup> Advance care plans are intended to meet people's wishes for care and to reduce anxiety for patients and family.<sup>35</sup>
64. Advance care planning is particularly important for people to maintain control as they approach older age,<sup>36</sup> enabling later-life services and rights to be understood and accessed if desired, and for the potential negative impacts of poor planning on the lives of older people and their carers to be significantly reduced.
65. However, research suggests that the practice of advance care planning in Australia is not common, particularly when compared with other planning documents such as wills.<sup>37</sup>
66. A 2017 Australian study assessed how many people aged 65 years or over had at least one advance directive on file. The study found a rate of 48% in residential care, 16% in hospitals and 3% in general practices.<sup>38</sup> Most of the directives were non-statutory documents. Less than 3% had a statutory advance directive outlining preferences for care, and only 11% had a statutory advance directive appointing a substitute decision-maker.<sup>39</sup>

<sup>32</sup> Exhibit 2-86, Adelaide Hearing 2, Swerissen Duckett Dying Well, GRA.0001.0001.0570 at 0583.

<sup>33</sup> Royal Commission into Aged Care Quality and Safety, *Background Paper 5 – Advance care planning in Australia*, 2019, p 6; JJ Rhee, NA Zwar and LA Kemp, 'Uptake and implementation of Advance care planning in Australia: findings from key informant interviews', *Australian Health Review*, 2012, Vol 36(1), pp 98–104.

<sup>34</sup> Exhibit 2-86, Adelaide Hearing 2, Swerissen Duckett Dying Well, GRA.0001.0001.0570 at 0583; KM Detering et al., 'The impact of advance care planning on end of life care in elderly patients: randomised controlled trial', *British Medical Journal*, 2010, 340, p 1.

<sup>35</sup> Exhibit 2-86, Adelaide Hearing 2, Swerissen Duckett Dying Well, GRA.0001.0001.0570 at 0583.

<sup>36</sup> Royal Commission into Aged Care Quality and Safety, *Background Paper 5 – Advance care planning in Australia*, 2019, p 12.

<sup>37</sup> Royal Commission into Aged Care Quality and Safety, *Background Paper 5 – Advance care planning in Australia*, 2019, p 5; B White et al., 'Prevalence and predictors of advance directives in Australia', *Internal Medicine Journal*, 2014, Vol 44(10), pp 975- 980.

<sup>38</sup> Royal Commission into Aged Care Quality and Safety, *Background Paper 5 – Advance care planning in Australia*, 2019, p 5; K Buck, K Detering, M Sellars, R Ruseckaite, H Kelly and L Nolte, *Prevalence of advance care planning documentation in Australian health and residential aged care services*, Advance Care Planning Australia Report, 2018, p 4.

<sup>39</sup> Royal Commission into Aged Care Quality and Safety, *Background Paper 5 – Advance care planning in Australia*, 2019, p 5; K Buck, K Detering, M Sellars, R Ruseckaite, H Kelly and L Nolte, *Prevalence of advance care planning documentation in Australian health and residential aged care services*, Advance Care Planning Australia Report, 2018, p 4.

### ***Promoting positive ageing***

67. There is a requirement for a shift in mindset towards that of positive ageing, and a culture in which planning for ageing is a normal part of planning for retirement.<sup>40</sup> People with a positive ageing mindset view ageing as a healthy, normal part of life that should be embraced.
68. We should all be thinking and planning for ageing and our future care needs much earlier in life. Research shows retirement is a particular opportunity for positive lifestyle change.<sup>41</sup>
69. We submit that life planning needs to be a proactive process. People should be encouraged to engage in healthy behaviours, to access good healthcare, and to manage their conditions well. An important first step is promoting health literacy and financial literacy to increase people's 'life planning' capacities and address the tendency to avoid thinking about ageing until middle age or later.<sup>42</sup>

### ***Health literacy***

70. In order to improve life-planning, a greater focus needs to be placed on educating the public about aged care, to encourage informal discussions about people's options and preferences for their own aged care, along with incentives and obligations to ensure that such discussions occur.<sup>43</sup>
71. As expressed in Adelaide Hearing 1 by Patricia Sparrow, CEO of Aged & Community Services Australia (**ACSA**):
- The familial relationship is critical to our health and wellbeing at all ages.... Staying engaged with older loved ones is the most important contribution families can make.
- An investment by individuals in health literacy and planning for older age needs to be encouraged and supported.<sup>44</sup>
72. There should be a public education campaign encouraging people to consider and discuss their aged care preferences with their families, informal carers or general practitioners.<sup>45</sup>

<sup>40</sup> Exhibit 1-3, Adelaide Hearing 1, NACA Submission Integrated Care at Home, RCD.9999.0001.00122,

<sup>41</sup> Submission of the University of Newcastle Research Centre for Generational Health and Ageing, Consultation Paper 1, AWF.660.00063.0001 at 0002.

<sup>42</sup> Submission of Uniting Care Australia, Consultation Paper 1, AWF.660.00147.0001 at 0018.

<sup>43</sup> Exhibit 2-86, Adelaide Hearing 2, Swerissen Duckett Dying Well, GRA.0001.0001.0570 at 0599.

<sup>44</sup> Exhibit 1-45, Adelaide Hearing 1, Statement of Patricia Lee Sparrow, WIT.0014.0001.0001 at 0014 [89]-[90].

<sup>45</sup> H Swerissen and SJ Duckett, 'What can we do to help Australians die the way they want to?', Medical Journal of Australia, 2015, Vol 202, 1, pp 10–11.

### ***The involvement of general practitioners***

73. All Australians aged 75 and over are eligible for an annual health assessment with their general practitioner. These assessments provide an opportunity to discuss a range of health issues, and are an opportunity to discuss aged care preferences. They should be.
74. We propose that measures are implemented to increase the role of general practitioners in the provision of information regarding the aged care system. This could become part of the annual health assessment process and may also include the provision of information regarding advance care plan to their patients.<sup>46</sup>

### ***Financial planning***

75. There should be a public education campaign for people to plan for their financial future and future housing needs.
76. The Future Care Study 2018 found that around 40% of older Australians are not confident they will be able to fund their future care needs.<sup>47</sup> Only 9% of older people have a financial or savings plan, and only 3% have sought financial advice regarding their future care.<sup>48</sup>
77. We have heard that people want to receive care in their own homes.<sup>49</sup> Relevant to this position, at Adelaide Workshop 1 on 10 and 11 February this year, Paul Versteeg of the Combined Pensioners and Superannuants Association (**CPSA**) told us that:
- We don't want to have a situation where people are forced to buy into a retirement village with independent living units ... at first contact we want them to start thinking about, "Is my house suitable for me?" That's – you know, people like to try and defend their independence by staying in the family home and it becomes a symbol of independence. If we can overcome that and encourage people to think rationally about, you know, what does the home do for you and what doesn't it do for you, that would be a big gain.<sup>50</sup>
78. Financial and accommodation planning should include arrangements for discussions on ageing.<sup>51</sup>

<sup>46</sup> Exhibit 2-86, Adelaide Hearing 2, Swerissen Duckett Dying Well, GRA.0001.0001.0570 at 0594.

<sup>47</sup> McCrindle, 'Future Care Study 2018', *Absolute Care & Health*, 2018, p 22.

<sup>48</sup> McCrindle, 'Future Care Study 2018', *Absolute Care & Health*, 2018, pp 4–6.

<sup>49</sup> See discussion below at Part 6.

<sup>50</sup> Transcript, Adelaide Workshop 1, Paul Versteeg, 10 February 2020 at T7715.14–20.

<sup>51</sup> Submission of Older Women's Network NSW, Consultation Paper 1, AWF.660.00139.0001 at 0002.

## **PART 4 Information and contact points**

### ***Proposals***

People in need of aged care should no longer have to depend on using the My Aged Care website and/or call centre to obtain access to aged care.

In addition to people using the website and call centre, the system should accommodate referral by health practitioners, social workers, local government employees and other responsible professionals.

The Australian Government should fund and support design and implementation at the national level, and at the local level, of education and information strategies to improve knowledge about aged care amongst those responsible professionals with whom older Australians have frequent contact and to encourage discussion about and consideration of aged care needs.

Note: in addition to the above information and contact points, we propose that the care finder network will be an important pathway to accessing aged care for those who want or need face-to-face assistance. This proposal is addressed in detail in Part 5, below.

### ***The need for 'no wrong door' access to aged care***

80. Currently, access to the aged care system is predominately through My Aged Care. My Aged Care was established in 2013 in partial response to the 2011 Productivity Commission's recommendations for a single gateway or entry point to access Australian Government-subsidised aged care services, and is 'the main vehicle we have for providing consumers with information about the system'. My Aged Care comprises 'a website, contact centre, assessment services, and an electronic referral service to connect consumers to care'.<sup>52</sup> In 2018-2019, there were over 1.47 million calls to the My Aged Care contact centre and over 3.6 million visits to the website.<sup>53</sup>
81. Commissioners Tracey and Briggs observed in the Interim Report that '[m]ost people put off the decision to seek help from, or accommodation within, the aged care system for as long as possible'.<sup>54</sup> It can be very confronting, as 'to make this decision means acknowledging, even if tacitly, their own increasing frailty and inevitable mortality'.<sup>55</sup>
82. Given the inherent difficulties of the circumstances that require an individual to make contact with the aged care system, it is imperative that the system

<sup>52</sup> Exhibit 1-23, Adelaide Hearing 1, Statement of Glenys Beauchamp, WIT.0022.0001.0001 at 0037 [166].

<sup>53</sup> Department of Health (Cth), *2018-2019 Report on the Operation of the Aged Care Act 1997*, 2019, p 18.

<sup>54</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1, p 122.

<sup>55</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1, p 122.

- be easy to access and to use. It is often difficult for people to work their way around the My Aged Care website to be able to search for services.<sup>56</sup> Older people can have trouble using the contact centre and the website, in that they face confusing and duplicative assessments and that they are not supported to connect to services.<sup>57</sup> Recent media reports indicate that ‘new figures provided to the Senate showed more than 110,000 calls to My Aged Care did not get through over the three years from 2016-17, with nearly 43,000 going unanswered in 2018-19 alone.’<sup>58</sup> It would appear, as observed in Interim Report, that ‘My Aged Care is not yet successfully working as the front door to the aged care system’.<sup>59</sup>
83. There was evidence, from people and organisations speaking for consumer groups, providers, workforce bodies and professional bodies at Adelaide Workshop 1, in support of designing more face-to-face support into the aged care system.
  84. We address this in Part 6, below, when we turn to our proposal for nationwide availability of face-to-face care finding and case management for those who need or want it.
  85. For example, Ms Patricia Sparrow, CEO of Aged and Community Services Australia (**ACSA**), observed that she is ‘pleased to see that we have talked about having face-to-face capacity in regions’.<sup>60</sup> Ms Sparrow notes that, although it was not recommended to be designed this way, the current system ‘has been designed on a call centre and a website which are really important features but it’s focused on only a small number of people needing that face-to-face support’.<sup>61</sup> Ms Sparrow sees the redesign as an opportunity to ‘flip that and give more people the face-to-face support’.<sup>62</sup>
  86. Likewise, Dr Nick Hartland, First Assistant Secretary responsible for home care policy in the Commonwealth Department of Health, is of the opinion that ‘there’s no doubt that aged care as a whole needs to have a much greater face-to-face presence and that has to take a number of forms’.<sup>63</sup>
  87. Professor Mark Morgan has told us of his vision for aged care: ‘of multiple access points [that lead] to the provider of that service, and the sort of

<sup>56</sup> Transcript, Adelaide Hearing 2, Paul Sadler, 18 March 2019 at T737.46-47.

<sup>57</sup> Transcript, Adelaide Hearing 1, Kaye Warrener, 21 February 2019 at T593.26-597.32; Transcript, Adelaide Hearing 1, Maree McCabe, 19 February 2019 at T405.31-406.2; T406.26-43. Exhibit 2-15, Adelaide Hearing 2, Statement of Josef Rack, WIT.0068.0001.0001 at 0004 [28]. Exhibit 2-4, Adelaide Hearing 2, Statement of Raelene Ellis, WIT.0083.0001.0001 at 0027 [154].

<sup>58</sup> Judith Ireland, ‘Aged care helpline: more than 100 calls a day went unanswered’ (Sydney Morning Herald, 17 February 2020), <https://www.smh.com.au/politics/federal/aged-care-helpline-more-than-100-calls-a-day-went-unanswered-20200212-p54000.html>, viewed 25 February 2020.

<sup>59</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1, p 129.

<sup>61</sup> Transcript, Adelaide Workshop 1, Patricia Sparrow, 10 February 2020 at T7675.8-10.

<sup>62</sup> Transcript, Adelaide Workshop 1, Patricia Sparrow, 10 February 2020 at T7675.11.

<sup>63</sup> Transcript, Adelaide Workshop 1, Dr Nicholas Hartland, 10 February 2020, T7700.16-18.

access point we're talking about would be the personal carer themselves, experiencing an unmet need, a health provider like a GP or hospital provider'.<sup>64</sup>

88. In light of this evidence, we submit, as Professor Kathy Eagar says in her submission on Consultation Paper 1, that there should be 'no wrong door'.<sup>65</sup>

### **Information**

89. We do not intend in this submission to address in detail the issue of shortcomings in the content and form of the information currently made available to people searching the My Aged Care website seeking access to aged care. As stated in the Royal Commission's Interim Report, what is required is information that will help people understand the assessment arrangements, how to get services organised, and what financial information they need to provide and to whom.<sup>66</sup> Further, meaningful information allowing a comparison of the performance of providers at the facility/service level is critical. In the absence of this, people are unable to make an informed decision about which service to select, defeating the purposes of "consumer directed care".
90. Therefore, in line with recommendation 4 of the Carnell and Paterson report, it is clear that there should be published provider performance ratings, from which the public may make comparisons between residential services in an area.<sup>67</sup> This should be in the form of star-ratings for performance differentiating providers at the service level. In line with *Counsel Assisting's Submissions on Workforce* (recommendation 1), those star ratings should incorporate or be informed by star-ratings for staffing levels on a casemix adjusted methodology.<sup>68</sup> The publication of performance ratings should be extended to home support and care services. The Department of Health intends to implement a differentiated star rating system from July 2020. It will be necessary to assess the adequacy of that information published via that system when it is revealed.<sup>69</sup>

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<sup>64</sup> Transcript, Adelaide Workshop, Professor Mark Morgan, 10 February 2020, T7697.23-26.

<sup>65</sup> Submission of Australian Health Services Research Institute, Consultation Paper 1, AWF.660.00121.0001 at 0001. See also discussion in Part 6 below.

<sup>66</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1, p 122.

<sup>67</sup> Exhibit 1-25, Review of National Aged Care Quality Regulatory Processes, Carnell and Paterson, October 2017, RCD.9999.0011.1833 at 1844.

<sup>68</sup> See: Submission of Counsel Assisting, Workforce Adelaide Hearing 3, 21 February 2020, RCD.0012.0061.0001 at 0034-0046 [134]-[184].

<sup>69</sup> Exhibit 8-32, Brisbane Hearing, Statement of Amy Elizabeth Laffan, WIT.0282.0001.0001 at 0024.

## **PART 5            Care finding and case management**

### ***Proposals***

People seeking and receiving aged care should be offered personalised help at all stages, including face-to-face assistance as required, as well as ongoing case management.

A new workforce of 'care finders' should provide this help (where the person wants or needs it) on a local basis throughout Australia. They should be trained in understanding the expression of wishes of older people (including via techniques of supported decision making). Care finders should also take into account the views and needs of informal carers.

Care finders should be able to share local knowledge with people they are assisting and give advice about different care options. Care finders should be able to arrange basic supports on an immediate interim basis and arrange comprehensive assessments. Their role should be facilitative and ought not to involve responsibility for making decisions about care planning (with the exception of immediate interim basic supports). They should have an ongoing case management role, the intensity of which should be largely driven by the preferences and needs of the people to whom they are allocated.

### ***Proposed institutional arrangements***

A new organisation should be established and funded by the Australian Government to exercise central administrative responsibility for care finding (and assessment). The new organisation should be staffed by Australian Public Service employees.

There are a number of options for recruitment of care finders:

- the new organisation could directly employ all care finders
- the new organisation could commission state governments, local governments, or community organisations, or a blend differing from region to region
- a blend of the two models – both direct employment by the organisation and commissioning may be appropriate, depending on local conditions.

Care finders can work in local communities and should utilise the trusted connections with diverse needs groups which some community-based organisations have established.



Care finders should be trained to understand the needs of diverse groups, and some care finders will have specialist expertise in this regard.

Care finders should work in close consultation with comprehensive assessment teams, and care finders and assessment team members to operate under the same branding to assist users.

### **Current system**

91. Older Australians and their families are not provided with a face-to-face assistance service when they contact My Aged Care.<sup>70</sup>
92. This was described by Dr Lisa Trigg in the Perth Hearing; when people turn to the aged care system, they are often in crisis and feeling desperate:
- Think about Shannon Ruddock yesterday who knew her father could get better care but I think the word she uses: *We were in a crisis situation, I couldn't do anything about it.* And that for many people is how they choose an aged care facility. You know, they've suddenly had a stroke, or a health crisis, their spouse has died and there's no longer somebody to live with. So there are any number of reasons why when you are looking for this type of care it is not a typical experience.<sup>71</sup>
93. In 2017, Healthdirect Australia and the Department of Health commissioned market research into the experiences of people with a home care package. The research revealed that people were often satisfied with the care and supports but had a low understanding of the process through which they have come to their current situation, and had relied heavily on informal carers to assist them in liaising with My Aged Care.<sup>72</sup> The key barriers were a lack of understanding about:
- a. The different types of care and supports available.
  - b. The key stages in securing a provider and the need to communicate key decisions back to My Aged Care in order to progress successfully through the process.
  - c. The need for people to actively manage different stages of the process against expectations of playing a more passive role in service arrangements.
94. At present, there is limited local or personal support for people to walk into a local office or call a local organisation to find out about the aged care system.

<sup>70</sup> Assessment involves face-to-face interviews with people seeking care. Submission of ACNA, Consultation Paper 1, AWF.660.00093.0001 at 0002, suggests that for a majority of people the combination of My Aged Care and RAS assessment works well in providing access to CHSP services, and that the problem of difficulty in navigating the system is largely limited to the HCP and residential care programs.

<sup>71</sup> Transcript, Perth Hearing, Dr Lisa Trigg, 28 June 2019 at T2814.41-2815.2.

<sup>72</sup> Exhibit 10-1, Melbourne Hearing 2, General Tender Bundle, tab 133, CTH.1000.0001.0676 at 0691.

Before someone can be referred to an assessor they must complete initial registration and screening online or by telephone. People often end up telling their story multiple times.<sup>73</sup> A person's experience of the system is limited by their knowledge of the system.<sup>74</sup>

95. The Department of Health has commissioned a limited trial of system navigators, and these trials are offering local supports that can meet people face to face. However, these services are limited, focusing on vulnerable populations.<sup>75</sup> Evaluation of the system navigator trials has not yet been completed.<sup>76</sup>

***Support to 'navigate' the system***

96. We submit that care finding should be a standard and integral element of the aged care program. Older people should have access, should they wish or need it, to face-to-face assistance in obtaining the care they need.

97. As described by Allied Health Professions Australia in its submission in response to Consultation Paper 1:

The way to simplify navigation of the aged care system for older Australians is to have direct and consistent access to someone who understands the system, and who can provide information about what services are available and what those can achieve.<sup>77</sup>

98. Dr Panter gave evidence in Melbourne Hearing 2 that having someone locally who you can visit or call, who can discuss ageing and aged care in detail, and who can step you through your options, would be of great benefit to the Australian system.<sup>78</sup>
99. At Adelaide Workshop 1, Paul Versteegen spoke of the need for the first contact person for older Australians to steer a person in the right direction but to also have detailed knowledge of what is available in that area.<sup>79</sup>
100. We propose that care finders should support people by explaining the assessment process, providing information on locally available aged care and linking people to providers. They should also refer people to assessment, and guide people through this process. After assessment, the care finder could continue to have a role in supporting people to access

<sup>73</sup> Exhibit 1-35, Adelaide Hearing 1, *Legislated Review of Aged Care*, RCD.9999.0011.0120 at 0885 [8.112].

<sup>74</sup> Submission of Allied Health Professions Australia, Consultation Paper 1, AWF.660.00081.0001\_0001 at 0005.

<sup>75</sup> Exhibit 4-1, Broome Hearing, General Tender Bundle, tab 35, CTH.0001.1000.6070; Exhibit 4-17, Broome Hearing, Statement of Jaye Smith, WIT.0128.0001.0001 at 0043 [171].

<sup>76</sup> Transcript, Melbourne Hearing 2, Jaye Smith, 9 October 2019 at T5533.34-41.

<sup>77</sup> Submission of Allied Health Professions Australia, Consultation Paper 1, AWF.660.00081.0001\_0001 at 0004.

<sup>78</sup> Transcript Melbourne Hearing 2, Dr David Panter, 10 October 2019 at T5658.4-21.

<sup>79</sup> Transcript, Adelaide Workshop 1, Paul Versteegen, 10 February 2020 at T7714.30-31.

- information and services, get the best from their aged care, and make changes as their needs and goals change. Such care finders would also have an important local educative role.
101. We agree with Baptist Care's submission in response to Consultation Paper 1 that the system should be in contact with individuals at an earlier stage by a navigator in their geographic region.<sup>80</sup>
  102. We agree also with what Ian Yates, Chief Executive of Council of the Aging (**COTA**) Australia, said in his evidence that the costs of funding this assistance should not be deducted from the funding provided for their ongoing support and care needs.<sup>81</sup>
  103. Many other submissions in response to Consultation Paper 1 also supported the adoption of an independent care finder in the aged care system.<sup>82</sup>
  104. Some, such as Care Connect, also contended for a wider role, incorporating care management. Care Connect submit that, 'provided they are also responsible for Care Management', they will 'dramatically improve the experience of, and outcomes for, older Australians and their families.'<sup>83</sup>
  105. Our proposal is to extend the role of the care finder to case management, but not to care planning. In this context, care planning involves the detail of particular kinds of personal and clinical care needed on a daily basis. In our submission, in light of the dynamic nature of the needs of older Australians, this planning needs to be performed by the day-to-day care provider.
  106. Ideally there would be no need for a care finder in a simplified system. However, we do not consider this to be a realistic aspiration, particularly in light of the potential vulnerabilities of the cohort of people who need aged care. Although in these submissions we have endeavoured to simplify the structure of the current aged care programs, a level of complexity remains 'behind the scenes'. 'Behind the scenes' there would be considerable complexity applying to arranging and conducting assessments, determining eligibility for supports and care, determining funding levels and prices, commissioning service providers, and arranging service delivery for individuals reflecting their eligibility.
  107. We submit that the main objective of a care finder should be to ensure that this complexity does not manifest as an obstacle for the older person and their carer and family. This should result in a program that responds to

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<sup>80</sup> Submission of Baptist Care, Consultation Paper 1, AWF.660.00077.0001\_0001 at 0005.

<sup>81</sup> Transcript, Adelaide Workshop 1, Ian Yates, 10 February 2020 at T7702.35-37.

<sup>82</sup> See for example: Submission of the Australian Commission on Safety and Quality in Health Care, AWF.660.00050.0001 at 0010-0011; Submission of COTA Australia, Consultation Paper 1, AWF.660.00131.0001\_0001 at 0008; Submission of Australian Commission on Safety & Quality Health Care, Consultation Paper 1, AWF.660.00050.0001\_0001 at 0010; Submission of the NT Office of the Public Guardian, Consultation Paper 1, AWF.660.00035.0001\_0001 at 0002; Submission of Home Instead Senior Care, Consultation Paper 1, AWF.660.00033.0002\_0001 at 0003.

<sup>83</sup> Submission of Care Connect, Consultation Paper 1, AWF.660.00012.0001\_0001 at 0001.

- people's needs with a continuum of support and care, adjusting as different needs arise (including with preventative interventions).
108. Carers NSW support this approach believing that the 'failure to incorporate adequate and appropriate support with service navigation in the design of a new aged care system may hinder its ability to meet its potential.'<sup>84</sup>
  109. We propose that the redesigned program should also adopt key components of Victoria's Access & Support Program, which is successful due to being designed and responding directly to identified community needs.<sup>85</sup> As part of the Access and Support Program, across Victoria, there are 10 advisers who support planning work to understand regional community need.<sup>86</sup> These advisers proactively work with data to analyse gaps including known population groups and people who may or may not be accessing services to then tailor approaches to better support populations, including making them feel safe to approach services.<sup>87</sup>
  110. Care finders should be recruited and trained, on a local basis, throughout Australia, and make use of local knowledge and trusted relationships built by community organisations with diverse needs groups. They could be integrated in other human services systems in their areas, particularly the Integrated Carer Support Service – Carer Gateway Regional Delivery Partners network contracted by the Department of Social Services – supporting the 'no wrong door' approach to aged care.
  111. We propose that care finder services should include:
    - a. supporting education and outreach on ageing and aged care in their local areas
    - b. arranging assessments to determine the level of funding required
    - c. linking people to short term supports or to mainstream or community services (i.e. housing, transport, health)
    - d. working with older people to assess their provider options, and to negotiate care and supports to be provided and prices
    - e. assisting with any ongoing needs, overseeing people's goals, their care plans
    - f. stepping in where the person seeks support or guidance, or where there are changes in circumstances.
  112. Care finders would be responsive to the needs and goals of the older people in their area. They would ensure continuity of support as an older person's needs change, or as they move between elements of the system

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<sup>84</sup> Submission of Carers NSW, Consultation Paper 1, AWF.660.00104.0001\_0001 at 0008.

<sup>85</sup> Transcript, Melbourne Hearing 2, Elizabeth Drozd, 10 October 2019 at T5641.11-14.

<sup>86</sup> Transcript, Melbourne Hearing 2, Dr Philip O'Meara, 10 October 2019 at T5624.5-6.

<sup>87</sup> Transcript, Melbourne Hearing 2, Dr Philip O'Meara, 10 October 2019 at T5624.5-24.

- (assessment, care at home, care in other settings) or interfacing systems and human services. They would interact with the health system on behalf of an older person, and maintain a relationship with general practitioners. This element of the proposal was supported by Bolton Clarke, which submitted that a person in this role could 'interact with the health system for irregular interactions'.<sup>88</sup>
113. Care finders would not, however, be funded as advocacy organisations.
  114. There are various options for recruitment of care finders. Care finders could be Australian Government employees, State government employees, local government employees or personnel based in local community organisations, including organisations that have special competencies in understanding the needs of particular diverse needs groups. As a general rule, care finders would not be associated with aged care providers.
  115. The role descriptions, functions, required qualifications and experience, of care finders will be developed through further work of the staff of the Royal Commission.
  116. Care finders would receive administrative support, direction and training from a single, central organisation. There is a question for further consideration as to the badging of the organisation. Our preliminary proposal is that it should operate under a new banner, not 'My Aged Care'.
  117. As an independent source of advice on aged care, we envisage that care finders would become trusted advisors who can support older people and their families. As mentioned above, in general, providers would not be able to be, or be employers of, care finders, to ensure independence and reduce any potential conflicts of interest. However, in some circumstances it could be necessary to use specialist providers who understand the diverse needs of the aged care population in a dual role as care finders,<sup>89</sup> and even for that role to extend to elements of assessment.<sup>90</sup>
  118. We propose that specialist providers would be better placed to act as care finders for Aboriginal and Torres Strait Islander communities, and in some remote or isolated communities. In these communities providers could also be assessors. There is also an argument that for some other diverse needs groups (such as people who are homeless, LGBTI people or those from culturally and linguistically diverse backgrounds), a provider with trusted links to the community of need could be suitably placed to be involved in care finder or assessment services, ensuring that care access services are culturally and psychologically safe and effective.<sup>91</sup>

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<sup>88</sup> Submission of Bolton Clarke, Consultation Paper 1, AWF.660.00068.0001\_0001 at 0003.

<sup>89</sup> Transcript, Adelaide Workshop 1, Graham Aitken, 10 February 2020 at T7733.30-40.

<sup>90</sup> Transcript, Adelaide Workshop 1, Graham Aitken, 10 February 2020 at T7734.21.

<sup>91</sup> Transcript, Adelaide Workshop 1, Bryan Lipmann, 10 February 2020 at T7705.7-12; Transcript, Adelaide Workshop 1, Samantha Edmonds, T7705.27-36.

119. In Adelaide Workshop 1, Samantha Edmonds, Managing Director of Aging with Pride, advised:

[I]f you don't have people that have that same diversity group, then you have to have a very skilled, educated workforce, the navigator or the care person, who understand cultural safety, who understand trauma-informed care, but also have the empathy and the compassion and that other understanding, as well. So it's not just the knowledge skills; it's the personal skills. And I think there needs to be a really good look at how that happens when hiring people.<sup>92</sup>

120. The Australian Commission on Safety and Quality in Health Care also acknowledged that in some locations the care finder may need to take on other roles.<sup>93</sup>

### ***Referral to assessment***

121. We propose that, on request or referral, care finders should be available to speak with people, face-to-face, learn about their needs (using interpreting and decision-support tools as required) and, if relevant, the needs of their carer.
122. The care finder should explain the assessment process, and explain the range of services that are potentially available in the local area, depending on the needs for which the person may be assessed.
123. The care finder should connect the person with, and guide the person through, the assessment process. They can facilitate referrals to, and act as a conduit of, information to the assessment body. They could work in close consultation with locally based members of a network of accredited assessment organisations and individuals.
124. Dr Nicholas Hartland of the Commonwealth Department of Health put it this way:

So I think you need to think of [care finders] as existing face-to-face capacity embedded in communities that people can approach, as well as a service offer that, once a vulnerable person gets into the system, will help them, guide them through the system. And in that respect, the whole thing should be geared to quickly getting people to assessment, so that you can start to think about what services that person needs.<sup>94</sup>

125. We support this approach. At the same time it is important to also recognise that not every person seeking their help will want or need ongoing care and supports. People need support to understand the benefits available to them

<sup>92</sup> Transcript, Adelaide Workshop 1, Samantha Edmonds, 10 February 2020 at T7699.7-12.

<sup>93</sup> Submission of the Australian Commission on Safety and Quality in Health Care, AWF.660.00050.0001 at 0011.

<sup>94</sup> Transcript, Adelaide Workshop 1, Dr Nicholas Hartland, 10 February 2020 at T7700.32-38.

and options to test out and try aged care before they have more complex and intensive care needs.<sup>95</sup>

126. We propose that the care finders are provided discretion to give interim eligibility for people to receive basic domestic and social supports, pending assessment. In cases where people wish to have basic supports on an ongoing basis, assessment will follow in due course, with timing dependent on the urgency of the case.
127. The care finder should have a continuing role during and after the assessment process in ensuring that information flows between the person and any provider they have been linked to. When there is a material change in the person's circumstances or condition, the care finder should be able to refer the person to the assessment team for reassessment.

### ***Linking***

128. We propose that, in addition to assisting with assessments, the care finder should help people to gain access to appropriate care and supports.<sup>96</sup> This could be done in a manner that respects the person's preferences, in the context of the constraints on 'choice' which apply in the aged care sector generally and particular local constraints on choice.
129. Care finders should receive training in eliciting and understanding people's choices. When examining the extent to which choice is available to people receiving aged care in the Perth Hearing, Dr Craig Sinclair, from the Centre of Excellence in Population Ageing Research, made the point that it is important to acknowledge the routine freedoms that the majority of able bodied, financially independent people enjoy in most areas of everyday life. The freedom to choose what to wear, when and what to eat, and how to fill one's free time are a routine experience for the majority of Australian citizens. The belief that such freedom will be compromised within the aged care system is likely to be a key driver of peoples' reported fear associated with accessing aged care.<sup>97</sup>
130. Once a person is within the aged care system, their choices are constrained to a greater or lesser degree, and in numerous ways. Further, at an individual level, the extent to which people accessing the aged care system can make the choices that the system asks of them varies from person to person.<sup>98</sup> A person's ability to access choice may be influenced by beliefs (held by

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<sup>95</sup> Submission of Amana Living Inc, Consultation Paper 1, AWF.660.00159.0001 at 0005.

<sup>96</sup> In some cases, linking advice and assistance is already provided by a member of the existing RASs and ACATs (See for example: Submission of Access Care Network Australia, Consultation Paper 1, AWF.660.00093.0001\_0001 at 0002, 0011; Submission of Catholic Health Australia, Consultation Paper 1, AWF.660.00040.0001\_0001 at 0004). We do not intend to preclude this from continuing, but we suggest that the care finder should be involved or informed where this occurs.

<sup>97</sup> Exhibit 5-30, Perth Hearing, Statement of Dr Craig Sinclair, WIT.0218.0001.001 at 0011.

<sup>98</sup> Exhibit 5-30, Perth Hearing, Statement of Dr Craig Sinclair, WIT.0218.0001.001 at 0013-0014.

- themselves and/or others) about their ability to make choices. One of the negative beliefs that can be held about older people is that they are not as capable of making decisions as younger people. People can also mistakenly assume that if a person cannot make a decision about one thing, they cannot make a decision about anything.<sup>99</sup> These beliefs can lead to older people disengaging, or being excluded, from making choices or decision making processes.<sup>100</sup>
131. When considering a population who may have impaired cognitive and/or functional abilities, and who are dependent on care providers for activities of daily living, 'choice' needs to be structured, presented and negotiated in an accessible way.<sup>101</sup>
132. This is not just a matter of importance in the role of the care finder. It is also critical for the proper provision of care. Informed and supported choice, including supporting people who need assistance to develop skills, knowledge and confidence to make informed choices about their care and their lives, is a core value of person-centred care.<sup>102</sup> Providing person-centred care to an individual with cognitive impairment takes longer than caring for someone who can participate in their care decisions. It requires specialist training and an aptitude and willingness to undertake this work. It takes longer to build rapport, understand client needs, and employ creative thinking and problem solving based on observation and team work to find activities that will work for that person. The Royal Commissioners heard that current funding does not allow for the extra time involved in this work.<sup>103</sup> This contributes to the justifications for increased skilled staffing levels, reflected by funding pegged to the costs of providing high quality care.

***Immediate interim access to basic domestic and social supports***

133. As mentioned above, our proposal envisages that the care finder would be provided the discretion to grant eligibility for a person to gain immediate access to basic supports on an interim basis, pending assessment.
134. In Adelaide Workshop 1, Dr Panter said that the early adoption of services should be encouraged.<sup>104</sup>
135. Immediate access would aim to support people with everyday living activities that they can no longer do for themselves, such as: managing finances, handling transportation, shopping, going to appointments and social

<sup>99</sup> Transcript, Perth Hearing, Dr Kay Patterson, 26 June 2019 at T2545.8-23.

<sup>100</sup> Exhibit 5-26, Perth Hearing, Statement of Dr Kay Patterson, WIT.0247.0001.0001 at 0007 [24].

<sup>101</sup> Exhibit 5-30, Perth Hearing, Statement of Dr Craig Sinclair, WIT.0218.0001.001 at 0013-0024.

<sup>102</sup> Exhibit 5-14, Perth Hearing, Statement of Jason Burton, WIT.0214.0001.0001 at 0014 [50]; Exhibit 5-5, Perth Hearing, Statement of Joanne Toohey, WIT.0168.0001.0001 at 0002.

<sup>103</sup> Exhibit 5-6, Perth Hearing, Statement of Kam Nelson, WIT.0207.0001.0001 at 0044 [180].

<sup>104</sup> Transcript, Adelaide Workshop 1, Dr David Panter, 10 February 2020 at T7725.27.



- activities, preparing meals, using the telephone or other communication devices, help with medications, doing laundry, housework, basic home maintenance, minor modifications to the home or minor assistive technologies. These supports should be provided in people's own homes and communities.
136. If the supports were to continue beyond a set time, comprehensive assessment would always be required, to ensure that the basic supports would be suitable from a holistic care perspective and so alternative or additional interventions could be considered by the assessment team. Assessment should be arranged at a time depending on care finder's estimation of the urgency of the case. The care finder could arrange interim supports following a discussion about a person's needs and goals, and by deciding whether the person would be appropriate for basic supports.
137. The care finder should not be able to approve personal care, nursing care or allied health. If a person is seeking help with their basic self-care tasks, such as eating, dressing, bathing, grooming, going to the bathroom, or their mobility, this may be because of an underlying condition which requires more intensive care, or may benefit from a preventative or rehabilitative intervention, so assessment would be required. If there is an urgent need for greater intensity of care, there would be a fast-track for comprehensive assessment to occur as soon as possible.
138. In discussing care options with older people, the care finder should also make a proactive effort to encourage people to consider alternative accommodation options if living at home is not the best option for them. At Adelaide Workshop 1 Paul Versteegen stated that at first contact, older people should be encouraged to consider whether their family home is suitable to age in.<sup>105</sup> Work is ongoing to determine the most appropriate service design for considering integrated housing and aged care needs—including examining the Assistance with Care and Housing subcomponent of the Commonwealth Home Support Programme—and any needs for funding directed at hoarding and squalor. At Adelaide Workshop 1, Mr Sadler and Dr Panter spoke positively of the flexibility and service provided by this program.<sup>106</sup>

### ***Case management***

139. The role of a care finder would be substantially more than helping the older person navigate the system. We submit that the care finder function should include case management, although we note that this was not universally

<sup>105</sup> Transcript, Adelaide Workshop 1, Paul Versteegen, 10 February 2020 at T7714.41-T7715.12.

<sup>106</sup> Transcript, Adelaide Workshop 1, Dr David Panter, 10 February 2020 at T7742.46-T7743.16. Transcript, Adelaide Workshop 1, Paul Sadler, 10 February 2020 at T7742.35-42.

- agreed in submissions to Consultation Paper 1.<sup>107</sup> There was general although not universal agreement that care finders should not be care coordinators; and that this should be the responsibility of care providers. There was disagreement as to whether the care finder needed to be clinically skilled.
140. At Adelaide Workshop 1, Ian Yates AM stated that COTA supported combining care finding, with assessment, and case management.<sup>108</sup> Case management could be seen to increase the interpersonal relations and individualism available within the aged care system. Case management is an option that would also go further to addressing the lack of understanding about what aged care supports people are entitled to, and how these supports and care can be obtained and managed. Case management can also be particularly effective if a person is entering the system early.<sup>109</sup>
141. A case manager helps individuals and families meet their needs by collaborating with them to achieve wellness and autonomy. The aims of case management systems can be succinctly defined as: 'to enhance the continuity of care and its accessibility, accountability and efficiency'.<sup>110</sup> The major components of the role that focus on the individual person are:
- a. assessment of need
  - b. development of a comprehensive service plan
  - c. arrangement of service delivery
  - d. monitoring and assessment of services<sup>111</sup>
142. It should be understood that we are not proposing that care finders should be responsible for care planning and co-ordinating the particular services required to meet a care plan. Short of this level of responsibility, however, the care finder should monitor whether the older person has successfully been linked with the service provider they have chosen and whether the relationship between service provider and older person is functioning.
143. Case management, as a component of the care finder proposal, could overcome some of the fragmentation of services and offer long-term, flexible support. The approach places emphasis on tailoring services to the needs of people, rather than fitting people into existing systems.<sup>112</sup>

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<sup>107</sup> Submission of Northern Metropolitan Region local Government Authorities, Consultation Paper 1, AWF.660.00078.0001\_0001 at 0007; Submission of Ward Medication Management, Consultation Paper 1, AWF.660.00069.0001\_0001 at 0008.

<sup>108</sup> Transcript, Adelaide Workshop 1, Ian Yates, 10 February 2020 at T7702.35-37.

<sup>109</sup> Transcript, Adelaide Workshop 1, Dr David Panter, 10 February 2020 at T7733.7-10.

<sup>110</sup> J Intagliata, 'Improving the quality of care for the chronically mentally disabled: The role of case management', *Schizophrenia Bulletin*, 1982, No. 8, Vol. 4, pp 655-674.

<sup>111</sup> G Shepherd, 'Case management', *Health Trends*, 1990, No. 22, Vol. 2, pp 59-61.

<sup>112</sup> J Renshaw, 'Care in the community: individual care planning and case management', *British Journal of Social Work*, 1988, No. 18, pp 79-105; V Beardshaw and D Towell,

144. The care finder would need to have some degree of ongoing or periodic contact with the older person. The level of contact dependant on an estimation of need. Acting as case manager, the care finder would follow the person through the complex changes they encounter as they go through the aged care system, as they age, and as they face dying and death. For this role to be influential, the care finder would need to have power in the system, and a connection to all providers in their area.

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'Assessment and Case Management: Implications for the Implementation of "Caring for People"', *London King's Fund*, 1990.

## **PART 6            Informal carer support services and respite**

### ***Proposals***

The Australian Government should fund and support information and local outreach to apprise informal carers of services available to support them in caring for older Australians, including infirm spouses and people living with dementia. The care finder network could be utilised for aspects of this work. In addition, flexible pathways for providing carers with support should be adopted including via community-based groups or ‘hubs’.

Comprehensive assessment for eligibility for aged care should give attention to the needs of informal carers of older Australians in their own right, leading to quarantined entitlements for informal carers to receive support services, such as counselling and training, and respite.

Respite should be overhauled by a substantial increase in the scope and scale, as well as ready availability, of different kinds of respite, and an appropriate framework of incentives for providers of respite should be implemented.

The Department of Social Service’s Carer’s Gateway should be linked to the systems by which respite is made available so that informal carers are not confronted by separate system and the task of attempting to co-ordinate disparate services in order to obtain help.

### ***Introduction: Australians want to stay living at home for as long as possible***

145. Since the Royal Commission’s public hearings began in February 2019, we have consistently heard evidence that older Australians do not want to enter residential aged care. Further, a survey conducted by the CPSA in 2015 indicated that 95% of people wanted to receive care in their own home.<sup>113</sup>
146. In recent decades, government policy has focused on supporting older Australians to receive care at home.<sup>114</sup> Nevertheless, Flinders University reports that Australia’s rate of use of residential care is high by OECD standards both as a proportion of other forms of aged care and as proportion of relevant age cohorts of the population.<sup>115</sup> Taken in light of the notorious waiting times in the national prioritisation system for allocation of high level home care packages to people who have been assessed as needing

<sup>113</sup> Exhibit 1-9, Adelaide Hearing 1, Statement of Paul Versteeg, WIT.0009.0001.0001 at 0005 [28].

<sup>114</sup> Exhibit 1-37, Adelaide Hearing 1, Department of Health, 2017–18 Report on the Operation of the Aged Care Act 1997, RCD.9999.0011.0001 at 0046-0047.

<sup>115</sup> Rehabilitation, Aged and Extended Care Group Flinders University, and THEMA Consulting, *Review of International Systems for Long-Term Care of Older People* (November 2019), published in February 2020 by the Office of the Royal Commission as *Research Paper 2*, at pp 40 and 42.

- them,<sup>116</sup> this suggests that there should be significant further scope to delay or prevent altogether the progression of many older people into residential care than is currently the case.
147. A critical element in the sustainability of home care in many cases is the care, supportive presence, and supervision provided by, an informal carer.

***Who are the carers of older Australians?***

148. Informal carers are the family and friends of older Australians, who often care for the older person in their own homes, as shared with the person they care for. In 2015 almost 2.7 million Australians, or 12% of the population, identified themselves as informal and unpaid carers. Around 420,700 are primary carers to people over the age of 65 and the caring is overwhelmingly done by women (68.1%).<sup>117</sup> Also in 2015, Carers Australia commissioned Deloitte Access Economics to review the volume of care being provided by informal carers. The results revealed that informal care accounted for 1.9 billion hours of care in 2015, which is the equivalent of each carer providing 13 hours of care per week. Deloitte Access Economics calculated the replacement value of that informal care to be \$60.3 billion (equivalent to 3.8% of gross domestic product and 60% of the health and social work industry in 2015).<sup>118</sup>
149. The accuracy of the figures listed in the above paragraph are contingent on people identifying as carers. Informal carers may not even identify as carers. Carers often see themselves as fulfilling a family role. Because of this carers may not understand or recognise when there is a need to seek help or be aware of various forms assistance that may be available.<sup>119</sup>
150. The focus of the Mildura Hearing, held in July 2019, was on understanding the role of carers with a particular focus on regional areas. The Commissioners also heard evidence of the role of informal carers in a remote Aboriginal community during our Broome Hearing. The Commissioners have heard from many daughters who perform caring roles for their elderly parents in the course of our public hearings. Carers have told the Royal Commissioners about the benefits of caring, including establishing close bonds with the loved one they care for as well as a sense of purpose. However, carers have also described feelings of exhaustion, grief and sometimes frustration. We also know that informal carers have reduced opportunities to participate in paid work and their own health and social

<sup>116</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1, p141-143.

<sup>117</sup> Australian Government, Australian Institute of Health and Welfare, *Informal Carers Snapshot*, 11 September 2019 <https://www.aihw.gov.au/reports/australias-welfare/informal-carers>.

<sup>118</sup> Exhibit 1-12, Adelaide Hearing 1, 'The economic value of informal care in Australia 2015', RCD.9999.0003.0001 at 0006.

<sup>119</sup> Transcript, Mildura Hearing, Dr Meredith Gresham, 30 July 2019 at T4003.46-4004.20; Transcript, Mildura Hearing, Associate Professor Hodgkin, 30 July 2019 at T4004.25-4005.9; Transcript, Mildura Hearing, Dr Phillipson, 30 July 2019 at T4005.13-29.

needs are often compromised as the needs of those they care for increase.<sup>120</sup>

***What support is currently available to informal carers?***

151. Currently, the Australian Government subsidises a range of services to assist people in caring roles, in the form of respite care, training and counselling. There is also financial support in the form of the Carer Payment, Carer Allowance and Care Allowance which informal carers maybe eligible for from Centrelink and the Department of Human Services. Veterans may also be eligible for financial assistance.<sup>121</sup> The financial supports that are available to carers are summarised in the Office of the Royal Commission's Background Paper 6.<sup>122</sup>
152. My Aged Care, which is administered by the Department of Health, is intended to facilitate planned respite. Respite is only available for approved care recipients being those who have been assessed by an ACAT or ACAS as needing residential respite care. Approved care recipients are entitled to 63 days of subsidised residential respite annually with a Home Care Package, with extensions of 21 days possible. There is no data available as to the extent that Home Care Packages are used for respite.<sup>123</sup> The Commonwealth Home Support Programme funds respite in other settings, including flexible respite, cottage respite and centre based respite. There are very few cottage respite providers or dedicated respite facilities in Australia. Ms Sue Elderton, National Policy Manager at Carers Australia, estimates that there were 100 cottage providers, across the whole of Australia in 2017/18.<sup>124</sup>
153. The CHSP includes subsidised respite programs provided via grant agreements. The same respite programs may be available to a person on a Home Care Package, but the package holder is charged on a full cost-recovery basis. If a person has insufficient funds available for respite in a Home Care Package then CHSP services may be used by that same person to access respite.<sup>125</sup> Where a person has inadequate funds in their Home Care Package and they don't have access to CHSP services, then accessing respite can result in trade-offs being made in meeting the costs of ongoing

<sup>120</sup> Transcript, Mildura Hearing, Senior Counsel Assisting Peter Gray QC, 31 July 2019 at T4154.33-4155.9; Transcript, Mildura Hearing, Dr Meredith Gresham, 30 July 2019 at T4006.24-42; Transcript, Mildura Hearing, Dr Phillipson, 30 July 2019 at T4007.43-4008.11.

<sup>121</sup> Exhibit 10-13, Melbourne Hearing 2, Statement of Elizabeth Cosson, WIT.0219.0001.0001 at 0023.

<sup>122</sup> The Office of the Royal Commission, *Background Paper 6 – Carers of Older Australians*, July 2019 at p8 – 9.

<sup>123</sup> Exhibit 1-11, Adelaide Hearing 1, Statement of Sue Elderton, WIT.0003.0001.0001 at 0006. We consider the role of data, or the lack there of, in aged care in Part 12 of these submissions.

<sup>124</sup> Transcript, Adelaide Workshop 1, Sue Elderton, 10 February 2020 at T7775.38.

<sup>125</sup> Transcript, Mildura Hearing, Xenofon (Fonda) Voukelatos, 31 July 2019 at T4103.35-4104.9.

- care for the care recipient. Perversely, the result may be that even though the older person has higher levels of need under a Home Care Package, the obstacles to obtaining respite are greater than if the person was in receipt of CHSP services.
154. The Department of Social Services is responsible for providing services other than respite for all informal carers, including those caring for people who do not receive any aged care. The Carers Gateway and the Integrated Carer Support System is run by the Department of Social Services with the purpose of providing access to education, counselling, and support services to carers. The Carers Gateway also offers emergency respite. The Carer Gateway operates a website and telephone service. There is no information communications technology (ICT) link between the Department of Social Service's Carer's Gateway and the Department of Health and My Aged Care or Centrelink, leaving it to carers to try to match availability of respite via My Aged Care with the availability of carer support services via Carer Gateway, which is a disincentive to access the necessary supports.<sup>126</sup>
  155. The Carer Gateway is a web and telephone based platform. It does not offer any face to face support for carers. There are practical and physical reasons which can obstruct a carer from accessing the Carer Gateway, including a person's physical limitations, no or poor internet connection, none or limited computer literacy and access to a computer, a reluctance to access to carer support from a website or telephone line.<sup>127</sup>
  156. Further, the current offerings of respite are reported to be limited and piecemeal. In particular, there is unmet need for flexible respite (as opposed to comparatively large blocks of time in residential respite).<sup>128</sup>
  157. Residential respite is the most widely used form of respite. In 2017/18, 2522 facilities across Australia provided residential respite.<sup>129</sup> More people are using respite than ever before. The number of respite days used in 2017/18 was 2 million, an increase of 120,000 days from the previous year.<sup>130</sup>
  158. Currently, respite in residential aged care facilities is often used as a 'try before you buy' or a first stage of permanent residential care.<sup>131</sup> In this respect, supply of respite beds can be contained to those who are at a stage of need for a more permanent option, and equally, those who are after

<sup>126</sup> Transcript, Mildura Hearing, George Sotiropoulos, 31 July 2019 at T4136.12-4138.20;

<sup>127</sup> Transcript, Mildura Hearing, Bonney Dietrich, 30 July 2019 at T3970.37-39; Transcript, Mildura Hearing, Catherine Thomson, 30 July 2019 at T3992.34-3993.23; T3998.9-26; Transcript, Mildura Hearing, Dr Lyn Phillipson, 30 July 2019 at T4029.44-4030.6; T4031.38-4032.6.

<sup>128</sup> Australian Government, Aged Care Financing Authority, *Report on respite for aged care recipients*, 2018, p 3.

<sup>129</sup> Commonwealth of Australia, Department of Health, *2018-19 Report on the Operation of the Aged Care Act 1997*, 2019, p 39.

<sup>130</sup> Commonwealth of Australia, Department of Health, *2018-19 Report on the Operation of the Aged Care Act 1997*, 2019, p 39.

<sup>131</sup> Exhibit 1-11, Adelaide Hearing 1, Statement of Sue Elderton, WIT.0003.0001.0001 at 0007.

shorter, more frequent periods of respite may find themselves unable to use their local residential aged care facility for respite.

159. There are no incentives provided by the aged care funding regime for approved providers of residential aged care to offer flexible forms of respite or to undertake reablement measures when an older person enters residential respite. Further, there are inadequate incentives even for the provision of residential respite, because of funding disparities that in recent years have come to affect residential respite. The entry of an individual for respite is as administratively burdensome as for a new permanent resident. The subsidy available to approved providers for residential respite has not kept pace with increases in resident acuity. By comparison, ACFI funding outcomes have kept better pace with increases in resident acuity. The outcome now is that an approved provider of a residential care service has an incentive to maximise the use of allocated places for permanent residential care recipients or people who are likely to become such residents, because a permanent resident will attract greater revenue and the 'on-boarding' costs of frequently admitting respite recipients will be avoided.<sup>132</sup>
160. During Adelaide Workshop 1, Ms Elderton said that respite was 'probably one of the most underdone areas of aged care'.<sup>133</sup> The need for respite is most pressing and obvious when it comes to dementia because of the often unrelenting burden of caring for a loved one living with dementia, but the difficulties in finding services with the skills to provide respite for people living with dementia can be extreme.<sup>134</sup> The 24/7 interminable cycle of care burden is particularly acute with dementia because of its progressive nature and its effect of the cognition of the older person and the indirect effects of this on the carer, including social isolation.<sup>135</sup> As informal carer Ms Kay Gray stated at the Mildura Hearing:
- As hard as caring is physically, the mental toll can be just as bad if not worse. This comes not just from the constant stress you find yourself under caring for the person 24/7, but you also experience a degree of ostracisation from society. It became impossible for me to travel to visit family as Clive deteriorated as there was no way that I could take him with me, or obtain respite care for short term periods of a few days.<sup>136</sup>
161. A 2015 survey of Disability, Aging and Carers reported that 58.9% of primary carers did not receive assistance from organised services within the previous six months, 35.1% were not satisfied or were unsure about their satisfaction

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<sup>132</sup> Exhibit 7-1, Mildura Hearing, General Tender Bundle, tab 26, RCD.9999.0124.0102 at 0127.

<sup>133</sup> Transcript, Adelaide Workshop 1, Sue Elderton, 11 February 2020 at T7754.42-7755.2.

<sup>134</sup> Exhibit 7-4, Mildura Hearing, Statement of Rosemary Cameron, WIT.0309.0001.0001 at 0008 [50]-[52].

<sup>135</sup> Transcript, Mildura Hearing, Dr Meredith Gresham, 30 July 2019 at T4024.33-47.

<sup>136</sup> Exhibit 7-16, Mildura Hearing, Statement of Kay Gray, WIT.0310.0001.0001 at 0003 [17].



- with what was available to them, 25.4% were unaware of the range of services available. 86.2% had never used respite.<sup>137</sup>
162. Current offerings of respite lack any additional measures of reablement. Respite should present as an opportunity to improve on the condition of the care recipient.<sup>138</sup>
163. Along with the increased number of older Australians expected to need care, the increasing prevalence of dementia in our aged population, there is likely to be a decline in the ability of informal carers to provide care. Ms Elderton identifies the factors which influence these trends as:
- the increasing number of women (the traditional providers of family care to the aged) with [sic] in employment
  - the number of families requiring two incomes to support themselves
  - families having children later than life than has traditionally been the case, making it harder to care for elderly parents at the same time as young children.
  - the rising rate of relationship breakdown and divorces later in life which impacts on the availability of partners to provide care.<sup>139</sup>

### ***Carers and the assessment processes***

164. Historically, the needs of informal carers were not given appropriate consideration in the aged care assessment processes. Dr Lyn Phillipson of the University of Wollongong stated at the Mildura Hearing:

At the commencement of the new HCP program it was not mandatory for ACATs [Aged Care Assessment Teams] to conduct an assessment of carer need in their own right. As a result, the needs of carers have frequently gone unacknowledged or been viewed as secondary to the needs of the package recipient. Since October 2018, the carer screen in the National Screening and Assessment Form became mandatory which is a welcome improvement in carer recognition. The focus however remains on carer assessment to determine the 'sustainability' of the caring relationship. As such the assessment still runs the risk of identifying carer needs, only at a time of crisis.<sup>140</sup>

<sup>137</sup> Australian Bureau of Statistics, *4430.0 - Disability, Ageing and Carers, Australia: Summary of Findings*, Australian Government, 2015, <https://www.abs.gov.au/AUSSTATS/abs@.nsf/DetailsPage/4430.02015?OpenDocument>, viewed 27 February 2020.

<sup>138</sup> Transcript, Mildura Hearing, Dr Meredith Gresham, 30 July 2019 at T4019.23-4020.3 and T4037.32-37.

<sup>139</sup> Exhibit 1-11, Adelaide Hearing 1, Statement of Sue Elderton, WIT.0003.0001.0001 at 0008 at [10].

<sup>140</sup> Exhibit 7-14, Mildura Hearing, Statement of Dr Lyn Phillipson, 19 July 2019, WIT.0287.0001.0001 at 0008 [36].

165. Ms Elderton stated that while the ‘trend is to include families and friend carers in the definition of consumers of aged care - this has not necessarily translated to the operational level’.<sup>141</sup> The *Carer Recognition Act 2010* (Cth) declares that carers should be considered as partners with other care providers in the provision of care, acknowledging their unique knowledge and experience. However, that rings hollow without frameworks to support carers, including providing carers with access to an assessment or services and a cultural change in attitudes to caring and carers.<sup>142</sup>

***The role of the locally based community supports***

166. Increasing the availability and accessibility of respite is only one part of sustaining the care relationship.<sup>143</sup> We propose that, in a redesigned aged care system, the supports that are available to carers needs to be publicised. Aside from having a role in educating the broader community as to what supports are available, it should also allow for carers to self-identify as carers. An important way of achieving this, especially in rural and regional areas, could be to support community based organisations possessed of local knowledge in their endeavours to publicise and reach out to those who need assistance, including those who may not yet realise that they have that need.<sup>144</sup> The care finders network should be expected to have local knowledge of services available for informal carers in their area, to be able to link informal carers with services and community support organisations, and open channels of referral from such organisations.

***How can carers be supported in their role?***

167. As we submitted in Mildura, informal carers of older Australians should have an easily understood, accessible and comprehensive system of support services that is geared towards preventing carers being harmed by the burdens of care before that happens. In order to support carers, there are twin aspects that ought to be considered together, firstly the importance of an assessment process which includes carers and secondly the importance of early preventative intervention. Carers should be included in any assessment process. Ms Elderton said that there is a need to reorient the assessment process to sustain the care relationship, not just for the carer to be a means of communicating with the (older) person.<sup>145</sup> We agree and submit that the assessment process must be re-oriented in this manner.

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<sup>141</sup> Exhibit 1-11, Adelaide Hearing 1, Statement of Sue Elderton, WIT.0003.0001.0001 at 0007 [10].

<sup>142</sup> Transcript, Mildura Hearing, Catherine Thomson, 30 July 2019 at T3990.34-41 , T3991.1-4.

<sup>143</sup> Transcript, Adelaide Workshop 1, Sue Elderton, 11 February 2020 at T7780.24-29.

<sup>144</sup> Exhibit 7-9, Mildura Hearing, Statement of Donald Laity, WIT.0313.0001.0001 at 0006-0008 [48] – [49] and [53] – [57].

<sup>145</sup> Transcript, Adelaide Workshop 1, Sue Elderton, 11 February 2020 at T7767.1-15; Carers Australia submission in response to Consultation Paper 1, AWF.660.00042.0001 at 0007-0008.

168. Evidence at the Mildura Hearing indicates that there are tangible and long term benefits to carers if they have a local support centre providing information, links to support services, respite options in the area, support groups and empathy if only in the form of a cup of tea and a debrief with someone who understands. The Carers Hub in Mildura is an example of such a community support.<sup>146</sup>
169. In addition to factoring carers into the assessment process, a redesigned system requires an approach that equips carers with necessary skills from the beginning of their caring journey and regular, flexible respite along the way. Respite should be supported at much earlier stages, in small and regular amounts and this will encourage the long term sustainability of the care relationship.
170. Preventative intervention is a matter of common humanity. Further, to leave out intervention that can re-able the older person is a missed opportunity. There is a strong economic rationale to look at ‘respite and the carer’s constriction as an investment in the system provides a ... strong economic rationale for it being properly resourced and delivered, not just treated as the tail end of the aged care system’.<sup>147</sup> However, the steps we take in the delivery of respite in a redesigned aged care system ought only to be seen as the beginning of ‘fixing’ respite.<sup>148</sup>
171. Finally, planned respite and other supports (including education, training, counselling, and psychosocial supports) for informal carers should not be deducted from the care recipient’s funding for ongoing care needs. Counsel Assisting submit that such supports and respite should be available as an entitlement in kind or be represented by a quarantined amount of the overall funding resulting from the comprehensive assessment process.
172. Various points of detail remain to be considered. For example, what precisely should the effect of the informal caring relationship be on the level of eligibility for funding for the care recipient’s ongoing care needs? In doubtful cases who ‘qualifies’ as an informal carer? What is the best approach when two people both have direct aged care needs and are caring for each other? And what existing assessment tools may be useful in informing this element of the design of the program?

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<sup>146</sup> Transcript, Mildura Hearing, Don Laity, 30 July 2019 at T3958.22 – 46.

<sup>147</sup> Transcript, Adelaide Workshop 1, Sue Elderton, 11 February 2020 at T7754.45-7755.2.

<sup>148</sup> Transcript, Adelaide Workshop 1, Sue Elderton, 11 February 2020 at T7755.4-6.

## **PART 7            Assessment**

### ***Proposals***

Assessments of eligibility for all aged care should be conducted by assessment teams organised as a network with coverage throughout Australia, and supported and funded by a single organisation.

That organisation should be the same one which employs or commissions care finders.

Open channels of communication should be established and maintained between the care finders and assessment teams of each area.

The assessment teams should consist of, or be able to draw upon, the full range of competencies and specialisations in aged care, and should be able to scale the team's resources flexibly to respond to the needs of the person requiring assessment.

Assessment teams should be able to rely on current assessments by treating clinicians.

The guidance and tools for conduct of assessments should be revised in order to:

- require assessment of the needs of informal carers in their own right, and for generation from the assessment of a quarantined entitlement to carer supports and respite
- emphasise the preferences of the person receiving care about their quality of life
- emphasise preventative and rehabilitating care objectives.

### ***Current processes***

173. As noted in the Interim Report,<sup>149</sup> under current assessment arrangements, a person needing care may need to be assessed by different assessment bodies and processes: the Regional Assessment Service (for CHSP) and an Aged Care Assessment Team/Service (for HCP), and then by the service provider if the person enters residential aged care. The person's information does not always make its way from the assessment services to their My Aged Care client record, resulting in inconsistent screening or multiple unnecessary assessments. These arrangements can involve 'wasteful duplication'.<sup>150</sup>
174. This problem is not new. Mr David Tune reported on the issue in his 2017 review:

<sup>149</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1 at p 137.

<sup>150</sup> Transcript, Adelaide Workshop 1, Professor Mark Morgan, 10 February 2020 at T7708.29.

Consumers reported frustration at having to repeat their story and answer questions many times over, particularly when their client record should have included this information from previous assessments. Consumers said they found the distinct assessments confusing and that the unnecessary duplication was a disincentive to access services.<sup>151</sup>

175. As was observed in the Interim Report,<sup>152</sup> Mr Tune recommended a more rigorous and integrated assessment model, with the first step being the amalgamation of Regional Assessment Services with Aged Care Assessment Teams, and later incorporation of the residential care assessment function which sets personal funding levels, and is currently undertaken by providers.<sup>153</sup>
176. On 31 December 2019, the Minister for Aged Care and Senior Australians noted that Commissioner Tracey and Commissioner Briggs had called for the integration of the assessment workforce and announced a tender process for a combined service in their Interim Report.<sup>154</sup>
177. Following the Ministerial statement on 31 December 2019, Commissioner Pagone stated in a media release on 14 January 2020 that the Royal Commissioners 'have not yet made recommendations about which sector or mechanism will best achieve an integration of Regional Assessment Services and the Aged Care Assessment Teams'.<sup>155</sup>
178. Based on media reports of comments the Minister for Health has reportedly made in the past week, it is now unclear whether that tender process will proceed.<sup>156</sup>

### **Proposal**

179. In order to avoid duplication, inefficiency and potential confusion on the part of the person seeking care, it is necessary that there be one overarching assessment body responsible for all forms of aged care eligibility.

<sup>151</sup> Exhibit 1-35, Adelaide Hearing 1, *Legislated Review of Aged Care*, 2017, RCD.9999.0011.0120 at 0885[8.112].

<sup>152</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, Volume 1 at 37.

<sup>153</sup> Exhibit 1-35, Adelaide Hearing 1, *Legislated Review of Aged Care*, 2017, RCD.9999.0011.0120 at 0885-0886.

<sup>154</sup> Senator the Hon Richard Colbeck, Minister for Aged Care and Senior Australians, 'Statement on ACT/RAS integration', Media Release, 15 January 2020, <https://www.health.gov.au/ministers/senator-the-hon-richard-colbeck/media/statement-on-acatras-integration>, viewed on 3 March 2020.

<sup>155</sup> The Honourable Gaetano Pagone QC, Statement by Royal Commission Chair on ACAT Privatisation, 14 January 2020, <https://agedcare.royalcommission.gov.au/news/Pages/media-releases/media-release-14-january-2020.aspx>, viewed 25 February 2020.

<sup>156</sup> C O'Keefe, "Unlikely to proceed": Hunt backs away from privatisation of aged care teams', *Sydney Morning Herald*, 28 February 2020, <https://www.smh.com.au/politics/federal/unlikely-to-proceed-hunt-backs-away-from-privatisation-of-aged-care-teams-20200228-p545e4.html>, viewed 3 March 2020.

180. Assessment needs to be ‘accurate, timely, responsive ... independent’<sup>157</sup> and ‘... consistent’.<sup>158</sup>
181. In order to ensure as much accuracy as possible, balanced with efficiency considerations, assessments should be conducted by teams who can draw upon the fullest possible range of expertise (including specialist clinical expertise), but in a manner that is scalable to the needs of the person.
182. In order to be sufficiently responsive, agile and timely in their work, the teams should be sufficiently well resourced to be able conduct assessments promptly. There should be public reporting and evaluation of timeliness against expected benchmarks so any underperformance or under-resourcing is transparently disclosed, and remedial action can be taken. Assessment must be responsive to changes in circumstances or condition, including responding to episodic needs with timely interventions aimed at restoring health and wellbeing (these interventions are not to be met out of people’s ongoing care budgets).<sup>159</sup>
183. Assessment should be independent from service provision.<sup>160</sup> This is an elementary check and balance measure. It has also been observed that it ensures equity of access.<sup>161</sup> The principle of ensuring that assessment is conducted separately from service provision may be subordinated in exceptional circumstances, addressed in more detail below, where leveraging existing relationships is necessary to ensure access to assessment for people with diverse needs.<sup>162</sup>
184. Aside from establishing eligibility for funding, the purposes of assessment include assembling information about the needs, preferences and goals of the older person and the informal carer (if any). Importantly, this information enables principled, effective and efficient planning and delivery of care and support.
185. Other purposes of the assessment function may include:
- a. Collection of data useful to the development of better quality, safer aged care services
  - b. Providing an additional point of contact with the aged care system: communicating the values, benefits and expectations of the system.

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<sup>157</sup> Submission of Aged and Community Services Australia, Consultation Paper 1, AWF.660.00170.0001 at 0008.

<sup>158</sup> Transcript, Adelaide Workshop 1, Sean Rooney, 10 February 2020 at T7710.12.

<sup>159</sup> Transcript, Adelaide Workshop 1, Dr Gill Lewin, 11 February 2020 at T7755.24-27.

<sup>160</sup> Transcript, Adelaide Workshop 1, Mike Woods, 10 February 2020 at T7677.21-25.

<sup>161</sup> Transcript, Adelaide Workshop 1, Dr Ricki Smith, 10 February 2020 at T7704.39; Transcript, Adelaide Workshop 1, Ian Yates, 10 February 2020 at T7704.37..

<sup>162</sup> Transcript, Adelaide Workshop 1, Samantha Edmonds, 10 February 2020 at T7699.14-20. Transcript, Adelaide Workshop 1, Brian Lipmann, 10 February 2020 at T7699.22-47. Transcript, Adelaide Workshop 1, Graham Aitken, 10 February 2020 at T7734.15-24.

- c. Providing a nexus for convergence of the multiple disciplines involved in delivering safe and high quality aged care for the individual
186. Assessment must promote capacity building and support people in activities of daily living, and strive to enrich people's quality of life through a reablement focus.<sup>163</sup> There may be important benefits in adopting an 'active' assessment model, that incorporates short-term intensive interventions which can reduce the need for ongoing care services.<sup>164</sup> One possibility in this regard is that before assessment for ongoing care is finalised, consideration should be given to the implementation of short term rehabilitative interventions.<sup>165</sup>
187. Assessment must be culturally safe and appropriate, informed by an understanding of cultural safety and trauma-informed care and delivered with empathy and compassion,<sup>166</sup> and accessible (recognising that cultural safety is an aspect of accessibility).

### ***Care Assessment Body and Network***

188. The timeliness, accuracy and consistency of assessment should be supported by a care assessment body and network.
189. As outlined above, we propose that assessments should be coordinated under the overarching direction, support and funding of one organisation, and should be delivered by accredited care assessment teams organised in a network with coverage across Australia. This should be the same organisation that will employ and/or commission care finders.
190. Assessment teams should be able to draw promptly on multi-disciplinary experience, including clinical expertise from State administered hospital-based specialists, according to the complexity of the person's needs.
191. The network could include the members of pre-existing assessment teams and the use of ACAT resources, appropriately adapted, where practicable.
192. There needs to be clear and reliable information channels between health professionals treating the person and the assessment body, and the assessment body may rely on current assessments by such professions.<sup>167</sup>

### ***Comprehensive Care Assessment***

193. Assessment needs to be comprehensive in response to the person's needs, and the resources and expertise called upon in each assessment should be

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<sup>163</sup> Submission of Access Care Network of Australia, 23 January 2020, AWF.660.00093.0001 at 24.

<sup>164</sup> Transcript, Adelaide Workshop, Dr Ricki Smith, 10 February 2020 at T7720.1-12.

<sup>165</sup> Submission of Silver Chain Group, Consultation Paper 1, AWF.660.00095.0001 at 0012.

<sup>166</sup> Transcript, Adelaide Workshop, Samantha Edmonds, 10 February 2020 at T7700.11-26.

<sup>167</sup> Transcript, Adelaide Workshop 1, Professor Mark Morgan, 10 February 2020 at T7697.22-T7698.13.

scalable according to the person's needs.<sup>168</sup> Assessment should involve face-to-face assessment taking into account the person's living environment and other relevant circumstances, and be conducted with a strong emphasis on the following principles:

- a. Respecting choice and dignity, including reasonable risk
- b. Prioritising the person's quality of life and wellbeing
- c. Restoring or maintaining functioning
- d. Sustaining independence
- e. Where the person has an informal carer, providing for the needs of the carer by a range of supports for the informal carer, and for respite needs
- f. Meeting the person's needs for cultural and personal safety.

### ***Material Changes and Reassessment***

194. When there is significant change in a person's apparent needs by reason of changes in circumstances or condition, there must be a reassessment.<sup>169</sup> Standardised triggers for reassessment should be determined.<sup>170</sup> Further, a reassessment could be requested by the person, or a referral for reassessment can be made to the assessment body by either the existing service provider or the care finder, or by a treating medical practitioner, nurse, allied health professional, relative or other responsible person. As with assessment, there should be no wrong door for reassessment.
195. Upon reassessment, it is possible that person currently receiving support and care in the home may become eligible for residential care. There is a need for careful attention to be given to the principles which should apply in such circumstances, including guidance for the care finder and assessors to understand and support the individual's decision. We submit that no one should be faced with the withdrawal of home support and care in these circumstances. At the same time, we acknowledge that profound issues about the safety of continued home care may arise in some circumstances. If the person chooses to enter residential care eligibility for certain kinds of services may change. Some services are suitable for care in the home but would cease if the person moves to residential aged care (for example, basic domestic support), but others would continue (for example, social activities and transport).

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<sup>168</sup> For ACATs, the assessment may require a multi-disciplinary approach. This can be achieved through case conferencing, joint assessments with other service providers where necessary, follow-up visits, cross referral, multi-disciplinary consultations, or appropriate delegation processes. See: Exhibit 11-1, Melbourne Hearing 3, General Tender Bundle, tab 74, CTH.0001.1001.3391 at 3417.

<sup>169</sup> Transcript, Adelaide Workshop, Gill Lewin, 11 February 2020, T7785.35-37.

<sup>170</sup> Transcript, Adelaide Workshop, Sean Rooney, 10 February 2020, T7710.12.



196. Reassessment is particularly dynamic in the rehabilitative and restorative context.<sup>171</sup>

Assessment isn't at one point in time in a restorative intervention, it's ongoing because as somebody regains capabilities and confidence, then the input that they require can be quite different and they can actually move on to completely different goals.

So that it's certainly not a set and forget. It's a dynamic process when somebody is attempting to regain, relearn, be able to function more independently again.<sup>172</sup>

197. In the rehabilitative/restorative context, reassessment based on outcomes are the 'absolute key in this model, continuous measurement and monitoring of the outcomes to ensure that what is trying to be achieved – and this is not only in terms of accountability for the funder, but absolutely critical for the older person themselves to be able to visualise the gains they're making and also for the provider'.<sup>173</sup> The provider needs feedback about what's working, which can come from reassessment processes.<sup>174</sup>

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<sup>171</sup> Transcript, Adelaide Workshop, Deborah Parker at T7786.05-09.

<sup>172</sup> Transcript, Adelaide Workshop, Gill Lewin, 11 February 2020, T7756.30-38.

<sup>173</sup> Transcript, Adelaide Workshop 1, Gill Lewin, 11 February 2020, T7756.45-T7757.3.

<sup>174</sup> Transcript, Adelaide Workshop 1, Gill Lewin, 11 February 2020, T7757.5-7.

## **PART 8 Wellness, reablement and rehabilitation in aged care**

### ***Proposals***

The Australian Government should fund and support the delivery of wellness, reablement and rehabilitation services to older Australians.

The type of services may include, but not be limited to:

1. occupational therapy
2. physiotherapy
3. nursing support
4. personal care
5. nutritional interventions
6. medication reviews
7. provision of technologies to help with day-to-day activities
8. minor home modifications
9. measures for addressing loneliness

The provision of such services tailored to individual needs should be explored for all older Australians, irrespective of whether they are in their home or in a residential aged care facility, and irrespective of their cognitive status or prognosis.

### ***Wellness, reablement and rehabilitation in the current system***

198. 'Wellness', 'reablement' and restorative or rehabilitative approaches have been shown in studies to optimise a person's functional and psychosocial independence, having extensive long-term benefits both at an individual and societal level.<sup>175</sup>
199. It is necessary to explain the terms 'wellness' and 'reablement', which have acquired an accepted meaning in health and aged care, at the outset.
200. Adopting a 'wellness' approach is based on the understanding that regardless of illness, disability or frailty, most people want to live as independently and autonomously as they can, and generally have the ability

<sup>175</sup> See, for example: B Beresford et al, 'Outcomes of reablement and their measurement: Findings from an evaluation of English reablement services', *Health and Social Care in the Community*, 2019, Vol 27, No. 6; Aged Services Unit, Health and Wellbeing Research Cluster, *New ways of restoring and supporting the independence of older people*, Southern Cross University and The Benevolent Society; J Francis, M Fisher and D Rutter, 'Reablement: a cost-effective route to better outcomes', *Social Care Institute for Excellence*, 2011; G Lewin, H Alfonso and J Alan, 'Evidence for the long term cost effectiveness of home care reablement programs', *Clinical Interventions in Aging*, 2013, Vol. 8, pp 1273-1281.

- to make advances in their social, emotional and physical wellbeing.<sup>176</sup> Wellness approaches actively encourage older people to improve their functional abilities by learning or re-learning the skills that are necessary for independent daily living.<sup>177</sup>
201. 'Reablement' aims to reverse or slow an older persons' functional decline. This approach is planned, goal-oriented and time limited. Reablement helps people to adjust to their functional loss, or develop confidence and skills to perform their daily living activities.<sup>178</sup> Its purpose is to regain peoples' abilities and build their independence.<sup>179</sup> Rehabilitation may be part of reablement services, or may be required following an episodic event.
  202. Beyond the rehabilitation services available within the health system, there are currently separate restorative programs specifically for older Australians including the Transition Care Programme, the recent Short-Term Restorative Care Programme and services under the Commonwealth Home Support Programme.
  203. The Transition Care Programme, which is funded by the Commonwealth with delivery managed by State and Territory governments, provides time-limited periods of goal-oriented therapy and services to restore functioning of older people after a hospital stay. Existing recipients of Australian Government funded residential or home care services, including Home Care Package and CHSP recipients, may be able to access this program, however it requires an assessment for eligibility coupled with a period of leave from existing services to enable this to occur.<sup>180</sup>
  204. The Short-Term Restorative Care Programme involves the provision of up to eight weeks of assistance to older Australians with the aim to help the person regain or keep their independence at home. However, a person cannot receive care under this programme if they are currently receiving permanent residential care or home care through a HCP.<sup>181</sup>
  205. Across aged care programs, notwithstanding aspirational sentiment in program objectives, the extent to which wellness and reablement measures have been implemented is somewhat uneven or patchy, and elements of the

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<sup>176</sup> Department of Social Services, *Living well at home: CHSP Good Practice Guide*, Australian Government, 2015, p 10.

<sup>177</sup> Community West and WA HACC, *Wellness Approach to Community Home Care*, Information Booklet, 2008, p 6.

<sup>178</sup> Department of Social Services, *Living well at home: CHSP Good Practice Guide*, Australian Government, 2015, p 10.

<sup>179</sup> Aged Services Unit, Health and Wellbeing Research Cluster, *New ways of restoring and supporting the independence of older people*, Southern Cross University and The Benevolent Society, p 2.

<sup>180</sup> Exhibit 14-1, Canberra Hearing, General Tender Bundle, tab 6, CTH.0001.1001.6625 at 6646 [3.5.4].

<sup>181</sup> Department of Health *About the Short-Term Restorative Care Programme*, <https://www.health.gov.au/initiatives-and-programs/short-term-restorative-care-strc-programme/about-the-short-term-restorative-care-strc-programme#who-is-eligible>

- current program design inhibit a wellness or reablement approach being taken.
206. The Department of Health's *Commonwealth Home Support Programme, Program Manual* identifies that a 'key feature' of CHSP is that it will:
- ...deliver services and support with a strong focus on wellness, reablement and restorative care on a short-term basis, or of an ongoing nature, or across a small number of time limited interventions, to maximise a client's independence.<sup>182</sup>
207. Successful implementation of this objective remains to be seen. In its *Wellness and Reablement Report Outcomes 2018*, the Department of Health stated:
- Although a requirement since July 2015, the department is aware that nationally many service providers are at different stages of implementing a wellness approach in their service delivery practices.<sup>183</sup>
208. From 1 July 2018, the Department of Health has implemented a range of new obligations on service providers funded under CHSP, said to 'provide greater focus on activities that support independence and wellness and provide more choice to consumers.'<sup>184</sup> The effectiveness of these further measures remains to be seen.
209. There are examples of reablement and wellness programs that have been implemented with success, although they have not yet been widely adopted. One such example is the Home Independence Program (**HIP**) in Western Australia. An extract of the evaluation of the HIP stated:<sup>185</sup>
- The Home Independence Program (HIP), an Australian restorative home care/reablement service for older adults, has been shown to be effective in reducing functional dependency and increasing functional mobility, confidence in everyday activities, and quality of life. These gains were found to translate into a reduced need for ongoing care services and reduced health and aged care costs over time. Despite these positive outcomes, few Australian home care agencies have adopted the service model – a key reason being that few Australian providers employ health professionals, who act as care managers under the HIP service model.
210. In Adelaide Hearing 1, Nicholas Mersiades, Director of Aged Care Catholic Health Australia, described the issue in the system as follows:

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<sup>182</sup> Exhibit 7-1, Mildura Hearing, General Tender Bundle, tab 55, CTH.1000.0002.4038 at 4052 [1.2.7].

<sup>183</sup> Department of Health, '*Wellness and Reablement Report Outcomes 2018*', Australian Government, p 2.

<sup>184</sup> Department of Health, '*Wellness and Reablement Report Outcomes 2018*', Australian Government, p 2.

<sup>185</sup> G Lewin, K Concanen, D Youens, *The Home Independence Program with non-health professionals as care managers: An evaluation*, June 2016.

The current aged care system has insufficient focus on reablement and wellness. There is evidence that improving or maintaining individuals' functional capabilities and overall wellness not only enhances quality of life, but also reduces care costs for government.<sup>186</sup>

211. The ACFI has been observed as being unable to ensure, and even discouraging, the provision of wellness and reablement services in residential aged care. At the Perth Hearing, Chris Mamarelis, the Chief Executive Officer of Whiddon, said in this regard:

The problem with the ACFI funding model for an organisation such as ours that is taking a wellbeing and a re-ablement approach, is ACFI incentivises acuity, it incentivises getting sicker, it incentivises getting more frail. And that's just counterintuitive to what we're doing as an organisation and what we're trying to achieve as an industry. So there's a really dangerous unconscious message that has been sent from the government through ACFI funding in – incentivising frailty and acuity.<sup>187</sup>

212. Ms Natasha Chadwick, CEO and Founder of Bellmere, shared this view, stating:

I also have concerns about the way that the Aged Care Funding Instrument (ACFI) provides a disincentive for reablement processes in residential aged care. By that I mean that the ACFI works by providing higher funding as clinical needs increase, with the approved provider able to seek to have a resident reassessed as the need arises.<sup>188</sup>

213. Wellness is connected with having opportunities for 'personal growth'. Also in the Perth Hearing, Dr Rungie, Director of the Global Centre for Modern Aging, said:

What we certainly notice in – in both residential aged care and in home care is there's almost no focus on working with people to encourage them to think about personal growth and, therefore, what kind of activity they might take up in this – in that space to learn something, and very little effort to connect older people to other old people who've successfully done that, so people can learn from one another by word of mouth... I do think that abandoning the notion of personal growth in people is very dangerous for the person and very likely to result in people becoming much more dependent, much more quickly.<sup>189</sup>

214. We submit that ageist views impact the perceived care needs of older people and that public education is required to change attitudes to aging. In Adelaide Hearing 1, Mr Yates, Chief Executive of COTA, stressed to the Royal

<sup>186</sup> Exhibit 1-50, Adelaide Hearing 1, Statement of Nick Mersiades, WIT.0011.0001.0001 at [75].

<sup>187</sup> Transcript, Perth hearing, Mr Chris Mamarelis, 25 June 2019 at T2435.24-30.

<sup>188</sup> Exhibit 6-53, Cairns Hearing, Statement of Ms Natasha Chadwick, WIT.0172.0001.0001 at [93].

<sup>189</sup> Transcript, Perth Hearing, Dr John Rungie, 26 June 2019 at T2595.34-45.

Commissioners the importance of a reablement approach, 'rather than assuming [older Australians] are on a conveyor belt where it's going to get worse and worse.'<sup>190</sup>

215. Similarly, education is required to better support people with dementia. In its Response to Consultation Paper 1, Dementia Australia submitted:

People with dementia need more opportunities to access such [reablement] services - the current assumption is that because people with dementia are experiencing a progressive decline, rather than experiencing a disease trajectory with an obvious restorative path, they are not suitable candidates for reablement. However, people with dementia should still be eligible for reablement approaches to enable them to make the most of their abilities, stay active and participate in meaningful activities. Adopting a reablement approach also reduces the sense of 'feeling helpless' - especially amongst people living with dementia, who experience a progressive loss in their abilities.<sup>191</sup>

***Proposals required***

216. Adelaide Workshop 1 revealed strong support among witnesses for the notion of a significant increase to wellness, reablement and rehabilitation services to encourage independence and greater quality of life for older Australians. On the design of the reform required, Mr Glenn Rees, Chairman of Alzheimer's Disease International, said '...reablement, if it's going to be transformative, needs to be across the totality of aged care.'<sup>192</sup> We agree.
217. We propose that wellness, reablement and rehabilitation services should be available, and be actively encouraged, throughout the aged care experience. The provision of such services tailored to individual needs should be explored for all older Australians, irrespective of whether they are in their home or in a residential aged care facility, and irrespective of their cognitive status or prognosis.
218. The type of services should include, but not be limited to:
- a. occupational therapy
  - b. physiotherapy
  - c. nursing support
  - d. personal care
  - e. nutritional interventions
  - f. medication reviews
  - g. provision of technologies to help with day-to-day activities

<sup>190</sup> Transcript, Adelaide Hearing 1, Ian Yates, 11 February 2019 at T63.1-3.

<sup>191</sup> Submission of Dementia Australia, Consultation Paper 1, AWF.660.00162.0001 at 0016.

<sup>192</sup> Transcript, Adelaide Workshop 1, Mr Glenn Rees, 10 February 2020 at T7685.30-31.

- h. minor home modifications
  - i. measures addressing loneliness.
219. In line with Access Care Network Australia's submissions in response to Consultation Paper 1,<sup>193</sup> older Australians should be encouraged during care finding and assessment to improve their functional capacity and community connections before finalisation of their assessments for ongoing care needs. The goals of the rehabilitation program should be set in close consultation with the person receiving the care, putting them in the centre of the process and encouraging autonomy and independence.

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<sup>193</sup> Submission of Access Care Network Australia, Consultation Paper 1, AWF.660.00093.0001 at 0003 [1].

## PART 9 Diverse needs in aged care

### *Proposals*

The Australian Government should fund and support the delivery of aged care services that recognises, understands, respects and responds to the diverse needs older Australians may have. This should be irrespective of whether aged care services are received in a person's home, community or residential aged care setting.

This requires a whole of system approach and diverse needs must be considered at every step.

220. Groups of people with diverse needs have a right to receive high quality and safe aged care irrespective of ethnicity, background, living circumstances or location. Groups of people with diverse needs include people from culturally and linguistically diverse backgrounds, of lesbian, gay, bisexual, transgender and intersex people, people who are separated from their parents, country and culture, including Forgotten Australians, former child migrants and the Stolen Generations, Aboriginal and Torres Strait Islander people, people who are homeless or at risk of becoming homeless, and our Defence Force veterans. Financial and social disadvantage can intersect with diverse needs.
221. All stages and processes envisaged in the redesigned aged care program must be designed to respond to these needs and to involve service provision, including information and contact points.<sup>194</sup> These stages and processes include information and contact points, care finding, assessment and reassessment, and service provision.
222. Under the proposed program redesign, as in the current aged care system, the principal service delivery mechanism should remain one involving markets. Those markets are to be carefully monitored and, where necessary, managed. Markets may be thin on the supply side, not just in a geographical sense, but also in the sense that there is thin supply of services appropriate for groups with diverse needs.<sup>195</sup> Thin markets for diverse groups may be caused by the provider type that is available, for example, people with a background of institutional trauma may be unwilling to access services delivered by government or a faith based organisation.<sup>196</sup> Thin markets may also be caused by the limited service types that are available, for example, in rural and remote areas, people may need an at-home nursing service and

<sup>194</sup> See: Transcript, Melbourne Hearing 2, Noeleen Tunny, 7 October 2019 at T5298.18-T5299.11; Transcript, Melbourne Hearing 2, Dr Duncan McKellar, 8 October 2019 at T5429.15-19; Transcript, Adelaide Workshop 1, Dr Kirsty Nowlan, 10 February 2020 at T7673.1-4.

<sup>195</sup> Transcript, Melbourne Hearing 2, Noeleen Tunny, 7 October 2019 at T5284.5-41.

<sup>196</sup> Exhibit 10-18, Melbourne Hearing 2, Statement of Heather Brown dated 1 October 2019, WIT.0537.0001.0001 at [8]-[9]; Exhibit 10-14, Statement of Janette McGuire, 29 September 2019, WIT.0527.0001.0001 at .0002 [17] - [18].



- podiatry, but the only options available in their community are for home maintenance and personal support.
223. In the course of the work being undertaken by the staff of the Royal Commission, there is dedicated consideration being given to groups with diverse needs, including Aboriginal and Torres Strait Islander aged care, and how to address thin markets. These submissions on program redesign do not address this work.
  224. What is clear from our work to date is that any program design should afford flexibility in the commissioning of approved providers to meet the needs of diverse groups. An example of this is that it may be necessary to select one preferred provider as the provider of last resort, in return for more generous base funding to achieve scale and guarantee sustainability and ensure the older person receives quality and safe aged care.
  225. We recognise that a uniform system of standard processes cannot meet the needs of all Australians. Separate submissions will be made later on the issue of when and how the overall system design should be varied to meet the needs of diverse groups.

## **PART 10 Home support and care – additional points**

### ***Proposals***

The current Commonwealth Home Support Programme, Home Care Packages Programme and Residential Care Programme should transition as soon as possible to a single program based on a single eligibility assessment process, where funding is demand-driven based on assessed need and does not involve rationing.

Eligibility for support and care in the home should be assessed holistically through the assessment process.

Basic supports that are in defined categories should be provided at the discretion of the care finder on an interim basis pending that assessment.

Flexible funding arrangements having regard to local conditions should be used to ensure that the spectrum of required home support and care services are available in all areas.

Care recipients should be offered assistance by their care finders to choose an appropriate provider to co-ordinate their services. Alternatively, people may choose to self-manage the home support and care they receive where there is a sufficient market in home support and care services.

### ***The current system for receiving support and care at home***

226. People receive support and care at home through either the CHSP or a HCP. The CHSP is intended to provide entry level care and support services to a large number of people to assist them in staying at home.<sup>197</sup> It does this through grants in the form of block funding to providers. A wide range of service types are available through CHSP including care services (such as personal care, allied health and nursing) and support services (such as for domestic and social activities). Currently, some community nursing and allied health services are available to older people with an assessed need through the CHSP, but access is variable.<sup>198</sup>
227. While the CHSP is complemented by the HCP, the HCP is designed for older people whose care needs exceed what should be provided under the CHSP.<sup>199</sup> In practice, however, people with a HCP can and do still use the CHSP to ‘top up’ their package—for example where someone with a Level 1

<sup>197</sup> Exhibit 7-1, Mildura Hearing, General Tender Bundle, tab 55, CTH.1000.0002.4038 at 4040.

<sup>198</sup> Australian Institute of Health and Welfare, Aged Care Data Snapshot 2019 – fourth release, 2019. Analysis by the Office of the Royal Commission of the ‘Home Support’ tab shows variance in the funding and amount of services by the services types of nursing care and allied health care across states and territories that does not align with population.

<sup>199</sup> Exhibit 7-1, Mildura Hearing, General Tender Bundle, tab 55, CTH.1000.0002.4038 at 4048.

- or 2 package has exhausted their package but still requires nursing or allied health care.<sup>200</sup>
228. A HCP is allocated to the older person at one of four levels.<sup>201</sup> The older person can choose their provider and make choices about the supports they receive. We submit that currently older people lack options for independent advice to assist them in making choices about appropriate providers and supports.<sup>202</sup> Further, the fees for case management or care coordination services vary between approved providers and can be of a considerable cost when compared with the costs of the services that are being provided.<sup>203</sup>

### ***Proposal***

229. The improvement and expansion of aged care in people's homes and their communities must be a major focus of any re-designed system.
230. The processes for obtaining eligibility for aged care should be integrated, irrespective of setting for care and level of need. We have earlier submitted that there must also be provision for people to have face to face time with a care finder. This should simplify the experience of people using the system.
231. The Australian Government has announced that CHSP and HCP will be combined, although it is not clear how or when this will occur.<sup>204</sup> We agree that the suite of services represented by the two programs should be available through single assessment and eligibility process.

### ***The role of consumer directed care in a redesigned aged care system***

232. Consumer directed care can empower older people and their families to determine what is right for them, and increase their expectations around the level of service, communication, quality and skills of staff.<sup>205</sup> However, the Royal Commissioners have also heard evidence about the disadvantages of consumer directed care.<sup>206</sup>

<sup>200</sup> Department of Health, Commonwealth Home Support Programme, Program Manual 2018-2020, *Australian Government*, 2019, p 67.

<sup>201</sup> Royal Commission into Aged Care Quality and Safety, *Interim Report: Neglect*, 2019, p 53.

<sup>202</sup> Transcript, Darwin and Cairns Hearing, Professor Johanna Westbrook, 11 July 2019 at T3265.33-36.

<sup>203</sup> Exhibit 2-15, Adelaide Hearing 2, Statement of Josef Rack, 4 March 2019, WIT.0068.0001.0001 at .0004 [33] and [34]. Exhibit 2-4, Adelaide Hearing 2, Statement of Raelene Ellis, WIT.0083.0001.0001 at 0027 [154]. Mr Rack, Ms Henderson and Ms Ellis all gave evidence regarding the difficulty encountered by care recipients and their families obtaining access to information about and understanding the benefits of the case management services they were being charged for.

<sup>204</sup> Department of Health, Portfolio Budget Statements 2019-20: Budget Related Paper No. 1.9, Health Portfolio, 2019, p 121.

<sup>205</sup> Exhibit 5-5, Perth Hearing, Statement of Joanne Toohey, WIT.0168.0001.0001 at 0013.

<sup>206</sup> Exhibit 5-5, Perth Hearing, Statement of Joanne Toohey, WIT.0168.0001.0001 at 0014, Transcript, Adelaide Workshop 1, Jane Mussared, 10 February 2020 at T7727.10-18.

233. Recognising and respecting a person's autonomy may be easier to achieve in the home care setting compared to the congregate care setting of residential care, but it is not any less important.<sup>207</sup> In the Perth Hearing, Dr Mike Rungie submitted that the introduction of choice and control into aged care policy for HCP was 'one of the most exciting reforms in aged care'.<sup>208</sup> However, he also said:

we don't know much about how people in home care are exercising this choice and control to make a difference to their lives... Anecdotally there does not seem to be much change to what's on offer.

...

These clients are vulnerable people and are likely to need substantial empowerment to be effective consumers e.g. working through purpose and maintaining independence as a frail person, explanation of new products and support to try them, learning from and with others, support to use technology.<sup>209</sup>

234. In Adelaide Workshop 1, Professor Deborah Parker, Professor of Aged Care (Dementia) at the University of Technology Sydney, provided the following:

Choice is around what sort of support from what kind of person or organisation you want. Choice doesn't have to be that, "I find and pay for my own services." Choice can be built into a coordinated case management service that should be offered from entry into the system.<sup>210</sup>

235. We submit that older Australians should have the opportunity, subject to appropriate safeguards, to self-manage their own home support and care needs where they are able to and choose to do so.
236. We submit that in order for an older person to be able to self-manage, there needs to be an assessment by the comprehensive assessment body that it is appropriate for them to do so. The care finder should remain active in a case-management role, and in the event of any change in the care recipient's circumstances or condition, the care finder may seek reassessment. In cases where home support and care is self-managed, there should be no single provider taking on the role of care co-ordinator and it is up to the older person to co-ordinate their own care.
237. Safety and quality regulation in this context would essentially consist of safeguards that apply in the commissioning of home care support and care

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<sup>207</sup> Exhibit 5-5, Perth Hearing, Statement of Joanne Toohey, WIT.0168.0001.0001 at 0004.

<sup>208</sup> Exhibit 5-29, Perth Hearing, Statement of Dr Mike Rungie, WIT.0158.0001.0001 at 0008 at [24].

<sup>209</sup> Exhibit 5-29, Perth Hearing, Statement of Dr Mike Rungie, WIT.0158.0001.0001 at 0008 [25]-[25].

<sup>210</sup> Transcript, Adelaide Workshop 1, Professor Deborah Parker, 11 February 2020 at T7786.5-8.

providers, consumer feedback and complaints frameworks, and general law consumer protection under the Australian Consumer Law.<sup>211</sup>

***Limitations on self-management of home support and care***

238. Self-management of home support and care will not always be possible.
239. In cases of thin markets, it will be necessary to commission particular providers as preferred providers or providers of last resort. Market evaluation in regional markets and in markets for supply of services to diverse needs groups should be conducted in order to determine when special, flexible funding arrangements are required to ensure coverage. Staff of the Royal Commission are formulating options for proposals for commissioning that will be examined during a hearing later in the year.

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<sup>211</sup> Competition and Consumer Act 2010 (Cth) Schedule 2.

## **PART 11      Innovative accommodation models**

### ***Proposals***

The Australian Government should make available incentives to providers to encourage a range of innovative accommodation models driven by choice. Incentives should be particularly directed at measures enabling older people to live in home-style accommodation where possible.

### ***The current system***

240. As outlined below, evidence before the Royal Commissioners indicates that many Australians would prefer aged care accommodation offerings that differ from the traditional large institutionalised style residential aged care facilities.
241. In the Sydney Hearing, the Royal Commissioners heard evidence from a panel of innovative providers comprised of Ms Tamar Krebs and Mr Jonathan Gavshon of Group Homes Australia, Ms Jennifer Lawrence of Brightwater Care Group and Ms Lucy O'Flaherty of Glenview Community Services. These providers all offer 24 hour care services, but do so in a manner that recognises the importance of the care environment to quality care for older Australians, particularly for those living dementia.<sup>212</sup>
242. Associate Professor Stephen Macfarlane, Head of Clinical Services for the Dementia Centre at HammondCare, gave evidence that for people living with dementia in residential care, poor design of the physical and social environment is one of the significant systemic causes of substandard care.<sup>213</sup> He explained that shortcomings in the built environment as well as deficits in the social environment, together with the approach of carers to those living with dementia, are some of the common problems his service encounters.<sup>214</sup>
243. The evidence suggests features of the current system restrict innovative accommodation models from developing.
244. Ms Krebs gave evidence that Group Homes operates traditional homes in traditional suburbs. It was explained that, due to the innovative nature of this model Group Homes can operate as an approved home care provider, but not an approved residential aged care provider.<sup>215</sup> Ms Krebs said that Commonwealth legislation could be revised to include group homes as a discrete category of service offering.<sup>216</sup>

<sup>212</sup> Transcript, Sydney Hearing, 14 May 2019, Tamar Krebs / Jonathan Gavshon / Lucy O'Flaherty / Jennifer Lawrence at T1571.33-1607.10.

<sup>213</sup> Exhibit 3-68, Sydney Hearing, Statement of Stephen Macfarlane, WIT.0125.0001.0001 at 0017 [77].

<sup>214</sup> Transcript, Sydney Hearing, Stephen Macfarlane, 15 May 2019 at T1767.19-24.

<sup>215</sup> Transcript, Sydney Hearing, Tamar Krebs, 14 May 2019 at T1577.18-42.

<sup>216</sup> Transcript, Sydney Hearing, Tamar Krebs, 14 May 2019 at T1577.35-T1578.16; See also Transcript, Sydney Hearing, Jonathon Gavshon, 14 May 2019 at T1602.19-25.

245. Throughout the public hearings, particularly the Broome Hearing and Melbourne Hearing 2, the Royal Commissioners have heard evidence that for many people with diverse needs and experiences, mainstream residential aged care facilities may not be appropriate. Alternative, specialist accommodation may be required for these people that better meets their needs.

246. For example, Ms Tunny, Acting Director, Policy and Advocacy Unit at the Victorian Aboriginal Community Controlled Health Organisation, described the Jimbelunga Nursing Home saying:

Given the proportion of Stolen Generation survivors who are in that facility and their fear of being caged in, the actual design of the facility takes into account their experiences and their conditions.<sup>217</sup>

247. Currently, providers can apply through an Aged Care Approvals Round (**ACAR**) to the Department of Health for funding for building or upgrading residential aged care facilities from the Rural, Regional and Other Special Needs Building Fund.<sup>218</sup> These capital grants can be allocated to providers who focus on residential aged care for people from special needs groups or concessional, assisted or low-means residents. However, the availability of these grants is limited.<sup>219</sup>

248. As mentioned earlier, people want to stay in their own homes. Greater access to aged care in the home is required. But as Dr David Panter, Chief Executive of ECH Inc, cautioned in Adelaide Workshop 1, while home care initiatives are beneficial for those fortunate enough to own their own homes, for many Australians this is not the reality. He said:

We are seeing more older people, particularly vulnerable older people, in rental accommodation, and we know from... our experience, there are huge challenges in getting landlords to agree to home adaptations and all too often we are seeing older people at the annual turn of the lease being moved out of that rental property because the landlord will not have handrails put in the bathroom.<sup>220</sup>

249. In Melbourne Hearing 2, Ms Fiona York, Executive Officer for Housing for the Aged Action Group, highlighted in her evidence the importance of independent living units to her clients. She explained that these houses are not residential aged care, rather they are classified as retirement living.<sup>221</sup> In relation to demand for these retirement living units, Ms York said the following:

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<sup>217</sup> Transcript, Melbourne Hearing 2, Noeleen Tunny, 7 October 2019 at T5297.43-45.

<sup>218</sup> *Aged Care Act 1997* (Cth), Part 5.1.

<sup>219</sup> See: *Aged Care Act 1997* (Cth), s 12-3; Exhibit 4-17, Broome Hearing, Statement of Jaye Smith, WIT.0128.0001.0001 at 0012[57].

<sup>220</sup> Transcript, Adelaide Workshop 1, Dr David Panter, 11 February 2020 at T7759.46-T7760.3.

<sup>221</sup> Transcript, Melbourne Hearing 2, Fiona York, 7 October 2019 T5343.31-40.

what we're seeing is that the independent living unit sector is a thing that people want, a place where they want to live in the community. It's usually connected in with different services. However, that sector hasn't really been supported by government for a long time, and it seems that it's changing, and it's very opaque and hard to get into.<sup>222</sup>

### **Reform required**

250. The Australian Government should make available incentives to providers to encourage a range of innovative accommodation models driven by choice. Incentives should be particularly directed at measures enabling older people to live in home-style accommodation where possible.

251. In its submission in response to Consultation Paper 1, the Commonwealth submitted:

The Department agrees with the paper that accommodation options need to become more diverse and innovative, with a shift towards less institutional and more home-like forms of care. This could include the delivery of aged care services in independent living units, supported accommodation and retirement village settings, which currently sit outside of the aged care legislative framework.<sup>223</sup>

252. This proposal is not intended to preclude the need to continue to invest in and improve the sub-acute care capacities of residential aged care, in a way that meets the needs of the increasingly aged cohort of Australians, many of whom have complex health conditions and who may be living with advanced cognitive impairment.<sup>224</sup> To the contrary, for many people with high acuity needs, or because of their own personal preference, highly supportive residential aged care may be the setting in which they can be provided the best possible care for their needs.

253. Further there is an obvious connection between reform of residential aged care provision and the availability of affordable housing. An older person who cannot find affordable housing may be left with little practical option but to enter residential aged care. Efforts need to be made by the Australian Government, perhaps in combination with State and Territory governments, to increase the availability of affordable housing for the elderly in which aged care can be more efficiently provided to them.

254. In this regard, the CPSA in its submission in response to Consultation Paper 1, said:

CPSA is of the view that, for aged care to be delivered in a way that is "affordable and sustainable, both for individuals and the broader

<sup>222</sup> Transcript, Melbourne Hearing 2, Fiona York, 7 October 2019 at T5343.42-46.

<sup>223</sup> Submission of the Commonwealth Government, Consultation Paper 1, AWF.660.00167.0002\_0001 at 0008.

<sup>224</sup> See, for example: Submission of the Commonwealth Government, Consultation Paper 1, AWF.660.00167.0002\_0001 at 0008.



community”, it is fundamental for the aged care system to achieve a high level of co-location of care recipients. Co-location (is maximized, scil) in nursing homes, but home care too can be delivered much more efficient and affordably to both individuals and the broader community if care recipients are clustered, as they can be in retirement villages, residential parks, manufactured home estates and in specific seniors housing developments. ... the design principles of Australia’s aged care system should reflect that this system needs to actively incentivise co-location of home care recipients to secure tenure.<sup>225</sup>

255. Innovative models of accommodation may cause organisational challenges arising from lack of scale, for example challenges with staff training. These organisational challenges require further consideration.
256. The form of suitable incentives will be the subject of further work by the staff of the Royal Commission in the coming months.

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<sup>225</sup> Submission of the Combined Pensioners & Superannuants Association, Consultation Paper 1, AWF.660.00109.0001\_0001 at 0003.

## **PART 12 Residential care – additional points**

### ***Proposals***

As also mentioned in Part 10: the current Commonwealth Home Support Programme, Home Care Packages Programme and Residential Care Programme should transition as soon as possible to a single program based on a single eligibility assessment process, where funding is demand-driven based on assessed need and does not involve rationing.

The transition should involve implementation of appropriate casemix based funding classification model for residential care:

- based on independent assessment by a comprehensive assessment team, not by the service provider, and
- where the levels of funding corresponding to those classifications must be linked to actual cost data ascertained by an independent pricing authority and determinations of the estimated cost of providing high quality care.

Funding should include entitlements in kind or a budget to cover basic support services on the basis of assessed need, including transport and social activities.

Responsibility for care co-ordination and planning should be clearly placed on the residential care provider, subject to ongoing consultation with the older person (including family and any authorised representative, and if the recipient chooses, the care finder) about their care and, where safe and practicable, adherence to the person's choices about their care.

Interventions that are independently assessed as necessary to sustain functioning, and to restore functioning and reable residents should receive separate funding, not deducted from residents' ongoing care budgets.

Providers should have an obligation to seek reassessment upon changes in circumstances, and should have an incentive to support reablement because of the extra funding that it would attract. There should be performance based loadings in light of reablement outcomes over time.

The requirement for provision of culturally and psychologically safe assessment, care planning and care delivery in light of diverse needs should be mandated in all services. Some diverse needs that could attract loadings or supplementary funding, where the needs in question reasonably require the incurring of greater costs, may still need to be identified. There may be scope in the way these loadings and supplements are granted to provide incentives specialist accreditation.

Loadings for higher cost in rural, regional and remote areas should also apply, to the extent that materially higher costs are demonstrated.

In cases of very thin markets, providers may receive guaranteed base funding in return for provider of last resort obligations.

***Current program design problems***

257. On the available evidence, it appears that:
- a. ACFI is probably no longer fit for purpose in light of increased acuity of people entering aged care, the fact that reassessment for different funding classification is a function exercised by providers, and the structure of its domains may generate distortions and perverse incentives<sup>226</sup>
  - b. funding for care does not reflect the real costs of providing high quality care<sup>227</sup>
  - c. there are gaps in funding for transport to appointments and activities and other basic supports<sup>228</sup>
258. There are issues to be explored at a later hearing as to whether other gaps or deficits in funding exist (for example in respect of administrative overheads),<sup>229</sup> and whether therefore incentives exist for care funding to be spent in meeting those deficits rather than on care.
259. There is a need for evaluation of, and incentives for, the providers' efforts to maximise the residents' wellbeing and quality of life, in light of the residents' preferences and choices, reasonably balanced with safety considerations.<sup>230</sup>
260. It is appropriate that residential care funding continue to be available to be expended on a pooled basis within residential aged care services to ensure

<sup>226</sup> McNamee J, Poulos C, Seraji H et al., *Alternative Aged Care Assessment, Classification System and Funding Models Final Report*, Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong, 2017, pp 7, 39.

<sup>227</sup> McNamee J, Poulos C, Seraji H et al., *Alternative Aged Care Assessment, Classification System and Funding Models Final Report*, Centre for Health Service Development, Australian Health Services Research Institute, University of Wollongong, 2017, p 7.

<sup>228</sup> See for example: Transcript, Darwin Hearing, Michelle McKay, 8 July 2019 at T2908.14-32.

<sup>229</sup> For instance the *Aged Care Financial Performance Survey* prepared by StewartBrown indicates that as at March 2019 administration costs had continued to rise a higher rate than CPI, and it is likely that these costs would continue to rise due to increased costs associated with the introduction of the new quality standards. See: Exhibit 13-20, Bupa South Hobart Tender Bundle, tab 295, RCD.9999.0273.0001 at 0018.

<sup>230</sup> See: Transcript, Sydney Hearing, Professor Ibrahim, 16 May 2019 at T1788.15-T1789.2; Exhibit 6, Sydney Hearing, Statement of Professor Joseph Ibrahim, WIT.0115.0001.0001 at 0024[17]; Submission of Flinders University, Consultation Paper 1, AWF.660.00152.0001\_0001 at 0014; See also Transcript, Adelaide Workshop 1, Dr Cutler, 11 February 2020 at T7774.32 regarding potential for incentive mechanisms.

investment in a stable workforce and high quality care<sup>231</sup> meaning that individualised acquittal of expenditure of care fund is not appropriate.

261. In our submission, a form of reporting and acquittal of aggregated care funding at the service level (that is, for expenses on all care provided in a particular period at a particular residential aged care facility) would be appropriate to ensure that there are incentives in place for the funding to be spent on care.<sup>232</sup>

### ***Proposal***

262. Under our program redesign proposal the key changes to the above program elements would be:
- a. A transition to a program that is demand-driven and does not involve rationing.
  - b. A transition to an appropriate casemix based funding classification model:
    - based on independent assessment by a comprehensive assessment team, not by the provider, and
    - where the levels of funding are linked to actual cost data ascertained by an independent pricing authority and determinations of the estimated efficient costs of providing high quality care.
  - c. Funding to include a budget to cover basic support services on the basis of assessed need, such as transport and social activities.
  - d. Responsibility for care co-ordination and planning to be clearly placed on the residential care provider, subject to ongoing consultation with the older person (including family and any authorised representative, and if the recipient chooses, the care finder) about their care and where practicable adherence to the care recipient's choices about their care.
  - e. The potential for aggregated reporting of care expenditure to be imposed as a condition of continued funding, acquittal-based adjustments linked to care funding, and different means testing arrangements. These topics will be explored in detail at the funding and financing hearing in April and May this year.
  - f. Interventions that are independently assessed as necessary to sustain functioning, and to restore functioning and reable residents should receive separate funding, not deducted from residents' ongoing care budgets. Providers should have an obligation to seek reassessment upon changes in circumstances, and should have an incentive to support

<sup>231</sup> Transcript, Adelaide Workshop 1, Annie Butler, 11 February 2020 at T7805.33-45.  
Transcript, Adelaide Workshop 1, Professor Deborah Parker, 11 February 2020 at T7807.45-7808.32.

<sup>232</sup> Transcript, Adelaide Workshop 1, Dr Henry Cutler, 11 February 2020 at T7764.16-23.  
Transcript, Adelaide Workshop 1, Jaye Smith, 11 February 2020 at T7763.11-21

reablement because of the extra funding that it would attract. Further, there should be performance based loadings in light of reablement outcomes over time.

263. In addition, as outlined above, the requirement for provision of culturally and psychologically safe assessment, care planning and care delivery in light of diverse needs should be mandated in all services. However, there will be some diverse needs that we propose should attract loadings or supplementary funding, where the needs in question reasonably require the incurring of greater costs. There may be scope in the way these loadings and supplements are granted to provide incentives for specialist accreditation. Loadings for higher costs in rural, regional and remote areas would also apply.
264. In cases of very thin markets, providers may receive guaranteed base funding in return for provider of last resort obligations.
265. As a result of these changes and the other proposals in these submissions, from the care recipient's perspective, there would be a simplified pathway to access residential aged care, assisted (if the individual wishes or needs it) by the care finder:
- a. The person's assessment would result in allocation of the person to a particular level of residential care, together with a budget for basic support needs.
  - b. The person, with the support of their care finder if they wish, would choose a residential care provider in their area, who would then become responsible for provision and/or co-ordination of holistic support and care based on the level of funding and basic support budget for which they have been assessed.
  - c. Care co-ordination and planning would occur on an ongoing basis in consultation with the person, and (if they wish) their family/representative and care finder. The emphasis will be on maximising the person's quality of life in accordance with their wishes, to the extent it is reasonably safe to do so. A budget be available for the person's social activities and transport, on the basis of the person's comprehensive assessment of wellbeing needs.
  - d. Any needs for maintenance of functioning, reablement and restoration would be assessed by a visiting member of the independent assessment team and would be funded without diminishing the person's ongoing care and basic supports.

## **PART 13      Standardised data collection and analysis**

### ***Proposals***

The Australian Government should implement a standardised data collection program designed on the 'collect once, use many times' principle.

The program must be designed to inform longitudinal evaluation at the user, provider, and system levels.

The data to be included in the program should include:

- service usage data in the full range of service categories relevant to aged care
- a comprehensive range of health, safety and quality outcomes data, including medication data
- diverse needs
- quality of life metrics
- transitions and interfaces with the health system in each jurisdiction

The Australian Government should fund and support the development of the Information Communication and Technology (**ICT**) systems, linkages with the Pharmaceutical Benefits Scheme and Medicare Benefits Schedule information systems, and linkages with other datasets available to the Australian Institute of Health and Welfare and other government bodies, needed to achieve the above goals.

The Australian Government should fund and implement a program of data collection and analytics to forecast demand for aged care services, in all the service categories relevant to aged care.

The Australian Government should fund and implement a program to ensure ICT connectivity between different government bodies providing services relevant to aged care, including the Department of Veterans Affairs and the Department of Social Services.

### ***Data collection and analysis in the current system***

266. Reliable data collection and its analysis is a fundamental necessity to ensure Australian's care needs are met in an efficiently operating system. Yet evidence before the Royal Commissioners highlights significant shortcomings in current processes.
267. Evidence before the Royal Commissioners has highlighted significant issues with data in aged care. There has been a failure to collect relevant data, to effectively use data that has been collected, and a failure to integrate available data across the system.

268. Data is a topic to be explored in greater detail through workshops later this year. At this juncture, Counsel Assisting raises a number of areas of concern by way of illustration of these problems, and flags the importance of considering the role of data in system design when framing recommendations.
269. In the Sydney Hearing, the Royal Commissioners received evidence about the lack of reliable data regarding the prevalence of use of restraints,<sup>233</sup> and the rates of prescribing antipsychotics in residential aged care.<sup>234</sup> Professor Brodaty, Scientia Professor, Centre for Healthy Brain Aging, University of NSW, explained that there is a lack of adequate reporting obligations placed on providers relating to these matters.<sup>235</sup> We agree.
270. The lack of clear and consistent data is not unique to restraint. A lack of open and transparent data on safety and quality outcomes in both residential and home aged care has been raised as a common concern across the public hearings. For example, Mark Cooper-Stanbury, a former employee of the Australian Institute of Health and Welfare stated in his submission in response to Consultation Paper 1 that ‘there is no comprehensive data on the outcomes of care, short of the negatively-oriented mandatory residential aged care quality indicators’.<sup>236</sup>
271. In Melbourne Hearing 2, many witnesses lamented the absence of reliable data collection and analysis, which is required to care for people with diverse needs and experiences. The importance of collecting and making information available at every point, not just for those who succeed in accessing aged care, but also for those who experience barriers in accessing care.<sup>237</sup>
272. Dr Hartland of the Department of Health also gave evidence at Melbourne Hearing 2 which highlighted gaps in information necessary to understand the operation of the CHSP. The Royal Commissioners were told that there is a lack of data about the people on the waiting list of packages. Also, for those receiving packages, there is an absence of data about how each person is spending their money.<sup>238</sup>
273. In Canberra, the Royal Commissioners heard evidence regarding issues with information exchange between residential aged care facilities and primary and allied health providers. Evidence from direct experience witnesses

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<sup>233</sup> Exhibit 3-68, Sydney Hearing, Statement of Stephen Robert Macfarlane, WIT.0125.0001.0001 at 0023 [113].

<sup>234</sup> Transcript, Sydney Hearing, Professor Murphy, 14 May 2019, T1652.15-16 and T1654.1-8.

<sup>235</sup> Transcript, Sydney Hearing, Professor Brodaty, 17 May 2019, T1902.30-37.

<sup>236</sup> Submission of Mark Cooper-Stanbury, Consultation Paper 1, AWF.660.00088.0001 at 0004.

<sup>237</sup> Transcript, Melbourne Hearing 2, Samantha Edmonds, 7 October 2019 at T5313.45-47; Transcript, Melbourne Hearing 2, Nathan Klinge, 8 October 2019 at T5389.11-36; Transcript, Melbourne Hearing 2, Mary Patetsos, 7 October 2019 at T5310.38-45.

<sup>238</sup> Transcript, Melbourne Hearing 2, Dr Nicholas Hartland, 9 October 2019 at T5585.19-30.

- highlighted the consequences for residents, people caring for them and their families arising from these issues.<sup>239</sup>
274. As identified in *Counsel Assisting's submissions on Workforce* (21 February 2020), the President of the Australian and New Zealand Society for Geriatric Medicine Dr John Maddison explained that, under current data limitations, it is difficult to model future demand for geriatricians.<sup>240</sup>
275. Professor Johanna Westbrook from the Australian Institute of Health Innovation at Macquarie University gave evidence at the Darwin Hearing that the Australian aged and community care sector does not collect data well. She said "Australia's aged care sector is data rich but information poor".<sup>241</sup> She explained that the sector tends 'to collect the same information in multiple different places in different datasets and this really limits our ability to use that data or to improve the quality of that data'.<sup>242</sup>
276. Concern has been raised about the quality of data in many areas across the system. First Assistant Secretary, Jaye Smith of the Department of Health acknowledged at Melbourne Hearing 2 that currently there is no evaluation of the claims made by providers on My Aged Care as to their specialisations such as servicing of special needs groups, noting that the Department has committed to exploring verification options as part of the Diversity Framework Government Action Plan.<sup>243</sup> Mr Smith told us:
- The Department agrees that we need to do a lot more to be able to quality assure the information that is on My Aged Care in terms of providers indicating that they're able to service particular special needs groups.<sup>244</sup>
277. Evidence before the Royal Commissioners highlights issues in regulation caused by a lack of data collection and sharing between government agencies. The Earle Haven case study examined at the Brisbane Hearing is illustrative of how failings in information sharing within the Commonwealth contributed to the failure by the Department of Health and the Aged Care Quality and Safety Commission to adequately identify the risks presented by the approved provider People Care in the lead up to the closure of the facility.

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<sup>239</sup> Exhibit 14-12, Canberra Hearing, Statement of Dr Carolyn Hullick and Dr Ellen Burkett, WIT.1298.0001.0001 at 0031 [12]; Transcript, Canberra Hearing, Catherine Anne Davis, 11 December 2019 at T7399.6-13; Transcript, Canberra Hearing, Dr Andrew Robertson, 12 December 2019 at T7551.37-40.

<sup>240</sup> Exhibit 11-66, Melbourne Hearing 3, Statement of John Brian Maddison, WIT.0484.0001.0001 at 0006 [40].

<sup>241</sup> Exhibit 6-22, Darwin Cairns Hearing, Statement of Professor Johanna Westbrook, WIT.0196.0001.0001 at 0004 [13].

<sup>242</sup> Transcript, Darwin Cairns Hearing, Professor Johanna Westbrook, 11 July 2019 at T3235.22-25.

<sup>243</sup> Transcript, Melbourne Hearing 2, Jaye Smith, 9 October 2019 at T5509.3-12.

<sup>244</sup> Transcript, Melbourne Hearing 2, Jaye Smith, 9 October 2019 at T5507.13-15.



278. Ms Tracey Rees of the ACQSC told the Royal Commissioners that due to the separate IT systems used by the Complaints Officers and the Quality and Monitoring Officers at the ACQSC, a Quality and Monitoring Officer would not be aware of a Complaints Officer's record unless deliberate action is taken pass it on.<sup>245</sup>

***Reform required***

279. There should be standardised data collection program carefully designed on the 'collect once, use many times' principle.<sup>246</sup> This program needs to include Quality of Life metrics and be designed to inform longitudinal evaluation at the user, provider and system levels. It should also encompass transitions and interfaces with the health system in each jurisdiction.

280. Dr Gill Lewin told the Royal Commissioners at Adelaide Workshop 1 that she always believed that 'there ought to be a minimum dataset that is collected across aged care.' However she emphasised the need to explain that this would require work and continued that:

'[it] takes a lot of skill in terms of designing the measures that are actually clinically useful, because if workers on the ground or clinicians are being asked to collect data that they don't think is meaningful to what they're doing, to be quite honest, it's likely to be rubbish.'<sup>247</sup>

281. The Aged Care Industry Information Technology Council in its 2017 document entitled A Technology Roadmap for the Australian Aged Care Sector notes that 'the absence of common standards, sector-level policies and common data collection... means it is difficult for individual organisations to benchmark their performance and identify needed improvements.'<sup>248</sup> The roadmap highlights that information technology is an enabler of integrated services between providers responsive to consumer directed care and encourages the sector to reach agreement on interoperability within and between organisations and the sharing of data with agreed standards.<sup>249</sup>
282. Efforts should be made to encourage interoperability of computer systems to facilitate ease of record sharing in aged care. As Dr Hullick and Dr Burkett recommended at the Canberra Hearing, the Commonwealth should:

... lead inter-jurisdictional co-operation that enables data linkage between My Aged Care and state/territory jurisdictional hospital clinical data systems to allow reliable and early identification of RACF residents

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<sup>245</sup> Transcript, Brisbane Hearing, Tracey Rees, 5 August 2019 at T4273.9-24.

<sup>246</sup> Transcript, Darwin Cairns Hearing, Professor Johanna Westbrook, 11 July 2019 at T3235.22-25.

<sup>247</sup> Transcript, Adelaide Workshop 1, Dr Gill Lewin, 11 February 2020 at T7755.1-5.

<sup>248</sup> Exhibit 6-1, Darwin Cairns Hearing, General Tender Bundle, tab 135, RCD.9999.0114.0001 at 0020.

<sup>249</sup> Exhibit 6-1, Darwin Cairns Hearing, General Tender Bundle, tab 135, RCD.9999.0114.0001 at 0021.

and older persons with home care packages to facilitate safe transitions of care.<sup>250</sup>

283. There is a need for establishment of a systematic and coordinated approach to improve identification, investigation, analysis and reporting of matters relating to safety of aged care residents to ensure sector wide learning. As recommended by Professor Ibrahim in the Sydney Hearing, this should be part of development of a broader national database on risks in residential aged care.<sup>251</sup> As suggested by Professor Westbrook's evidence in the Darwin Hearing, established clinical indicators could be used to identify outlier facilities.<sup>252</sup>
284. Collected data must also be transformed in a way that makes it usable to consumers and stakeholders. Professor Radcliffe's evidence in Adelaide Workshop 1 raised new ways to think about how data to measure quality of life can be explored,<sup>253</sup> and how that data can be publicly reported to inform consumer choice.<sup>254</sup>
285. Further, there is also a need for radical improvement in data collection which would enable more accurate prediction of demand for aged care and more accurate assessment of whether aged care services are meeting demand. For example, presently, there is no national level data collection about the rates of dementia diagnoses.<sup>255</sup>
286. On the supply side, there is no national level data which maps variability in the level of accessibility of aged care services between localities of Australia. National mapping of this kind would be a critical first step toward systematically addressing deficiencies by targeted interventions to augment service availability in thin markets.<sup>256</sup>

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<sup>250</sup> Exhibit 14-12, Canberra Hearing, Statement of Dr Carolyn Hullick and Dr Ellen Burkett, WIT.1298.0001.0001 at 0031 [12].

<sup>251</sup> Exhibit 3-70, Statement of Joseph Elias Ibrahim, WIT.0115.0001.0001 at [69]-[72]; Transcript, Sydney Hearing, Professor Joseph Ibrahim, 16 May 2019, T1803.30.

<sup>252</sup> Transcript, Darwin Hearing, Professor Johanna Westbrook, 11 July 2019 at T3252.26-37.

<sup>253</sup> Transcript, Adelaide Workshop 1, Professor Julie Ratcliffe, 11 February 2020 at T7761.5-11.

<sup>254</sup> Transcript, Adelaide Workshop 1, Professor Julie Ratcliffe, 11 February 2020 at T7760.43-46.

<sup>255</sup> Transcript, Sydney Hearing, Glenn Rees, 13 May 2019 at T1546.6-29; Exhibit 3-41, Sydney Hearing, WHO Global action plan on the public health response to response 2017-2025, RCD.9999.0050.0001 at 0019 [87].

<sup>256</sup> Transcript, Mudgee Hearing, Dr Rachel Winterton, 5 May 2019 at T6452.15-46; Exhibit 12-15, Mudgee Hearing, Statement of Dr Rachel Winterton, WIT.0589.0001.0001 at 0014 [32.f]; Transcript, Mudgee Hearing, David Hallinan, 6 May 2019 at T6558.8-33.

**PART 14      Next steps**

287. These submissions will be published on the Royal Commission's website today. Submissions in reply are invited by 18 March 2020. The website will contain details of how those submissions can be made.

Counsel Assisting the Royal Commission into Aged Care Quality and Safety

4 March 2020