

Royal Commission into Aged Care Quality and Safety

Submissions by the Commonwealth on
Melbourne Hearing 1:

Younger people in Aged Residential Care

25 September 2019

MELBOURNE HEARING 1 – SUBMISSIONS OF THE COMMONWEALTH

YOUNGER PEOPLE IN RESIDENTIAL AGED CARE

A. BACKGROUND

- 1 The Commonwealth provides the following submissions on the specific matters raised by Counsel Assisting in oral closing submissions for Hearing 9 in Melbourne (the **hearing**). The focus of the hearing was younger people in residential aged care (**YPIRAC**), in particular:¹
 - (a) the policy responsibilities of the aged care system, the social service system and health systems;
 - (b) the interfaces between the aged care system, social service system and health systems;
 - (c) the profile of younger people in residential aged care and any specific circumstances which drive the admission of younger people into residential aged care;
 - (d) the care of a younger person while they are in a residential aged care facility, and how this may impede their exit from residential aged care;
 - (e) the special challenges faced by younger people seeking appropriate accommodation; and
 - (f) the nature of services typically provided to younger people in residential aged care.
- 2 These submissions concern three main areas that were the subject of adverse comments by Counsel Assisting during his closing address (as set out and responded to below):
 - (a) The Action Plan and its targets, and in particular any failure to properly consult with States and Territories when the Action Plan was conceived;
 - (b) The Commonwealth government's "complete lack of will" and suggested failure in prioritising younger people in aged residential care; and
 - (c) Specialist Disability Accommodation (**SDA**), including apparent delays by the National Disability Insurance Agency (**NDIA**) in reaching decisions relating to participants in the National Disability Insurance Scheme (**NDIS**)² accessing SDA.

B. INTRODUCTION

- 3 The situation of younger people living in residential aged care is a grave and persistent problem. It remains an issue requiring urgent redress. It is one which the Commonwealth has failed to resolve adequately in the past.
- 4 Such living arrangements are singularly inappropriate for young people who wish to live on their own terms, in their own dwellings, and with independence in the community. As was properly conceded in the evidence of Mr Lye, this is an issue into which the Commonwealth has previously failed to make sufficient inroads.³ Previous efforts and measures have not had the scope, in funding and design, to

¹ See the Aged Care Royal Commission's website, in particular the YPIRAC hearing page which is accessible at <https://agedcare.royalcommission.gov.au/hearings/Pages/hearings/2019/melbourne-hearing-1.aspx>

² The background to the NDIS is set out in the NDIA's response to NTG-0354 at [1] to [12].

³ T4938: 38.

cope with the problem by reducing the cohort or consistently diverting young people into appropriate accommodation before they reach the aged care system.

- 5 The evidence is also clear, and the Commonwealth accepts, that more detailed data is required to understand the characteristics and needs of this cohort to ensure they are properly accommodated, as well as to prevent their entering residential aged care in the first place. Work is currently underway to achieve that necessary knowledge and analysis.⁴
- 6 The evidence heard by the Royal Commission demonstrates that the Commonwealth now has a foundation, through the rollout of the NDIS, to address this issue on a scale and in a manner not previously possible. The Commonwealth is committed to using the NDIS to improve the lives of this cohort by supporting them to live as they would choose, and to ensure they have the supports in place for that choice to be meaningful. The NDIS provides funding to pursue these objectives.
- 7 However, the reality is that these reforms will take time to properly and sustainably implement. Residential aged care will continue to be the form of accommodation used by some younger people, whether because they are existing residents who choose not to leave, or because their circumstances, such as homelessness, mean that it is the only care in which they can be reasonably placed. It follows that an absolute and unqualified goal of having all younger people removed from residential aged care is both unrealistic and inconsistent with their own right to choose.

C. ACTION PLAN

“The action plan is relatively recent, but it appears to have been completed without proper consultation with all interested parties and without a full understanding of exactly who is in the target group. State Governments, as we’ve heard, were, evidently, not consulted.”⁵

...

“The action plan relies on the co-operation of the states and territories, and yet, as we’ve heard, the Commonwealth did not consult with the states and territories before announcing it. The action plan’s stake-holder reference group lacks members from the states and territories”⁶

- 8 The Commonwealth accepts that the States and Territories were not consulted on the design of the Government’s Younger People in Residential Aged Care Action Plan (**Action Plan**) prior to it being announced on 22 March 2019. However, not consulting with States and Territories *prior to* the Action Plan coming into existence does not mean that the States and Territories have not had a role to play in the Action Plan after its announcement. Nor should it be thought that the States and Territories have not had a role to play on an ongoing basis. It also does not follow that the Action Plan is necessarily flawed as a result.
- 9 It is important to note the following:
 - (a) **States and Territories are consulted through other forums.** There are a range of mechanisms for engaging State and Territories in relation to the Action Plan, including through Disability Reform Council working groups. The Commonwealth is in discussion with States and Territories on several important initiatives which support the Action Plan, including discussions on

⁴ Rundle at T5065 L12 and T5074 L46; McNaughton at T5013 L11.

⁵ T5251:L4.

⁶ T2521:L40.

the Health and NDIS interface, strategies to improve hospital discharge processes and work around boosting specialist disability accommodation.

- (b) **Stakeholder Reference Group.** The Project Board of the Action Plan may consider expanding the membership of the Stakeholder Reference Group (**SRG**) at any stage over the lifetime of the Action Plan, should the need arise. For example, the Department of Social Services (**DSS**) recently invited representatives from Aged & Community Services Australia and Uniting Communities to join the SRG. Further, the SRG may consult with relevant stakeholders at any stage during the implementation of the Action Plan on an ad hoc basis, including with the States and Territories. This means States and Territories could be represented on the SRG and the Commonwealth notes that discussion regarding the inclusion of representatives from State and Territory governments is still under consideration by the SRG.
- (c) **Key stakeholder groups were consulted.** While States and Territories were not consulted in developing the Action Plan, DSS and NDIA consulted with several other groups of key stakeholders to help inform the various elements of the Action Plan. Stakeholders included the YPINHA, YoungCare, Summer Foundation and Synapse.
- 10 Having regard to the above matters, the Commonwealth submits that the focus of all involved is on achieving the goals in the Action Plan and how the Commonwealth can meaningfully engage with the States and Territories in achieving those goals going forward, including through the SRG and other forums. As Counsel Assisting correctly notes, the Action Plan is relatively recent and there is still opportunity and time to engage with many stakeholders. Commonwealth departments are committed to ongoing engagement with stakeholders to ensure successful implementation of the Action Plan is achieved, including with the States and Territories.

“The action plan in this regard has come to the attention of the Australian Human Rights Commission. In its July 2019 submission to the United Nations on Australia’s compliance with the convention [in Article 19 of the United Nations convention on the rights of persons with disabilities], the Australian Human-Rights Commission recommended that the action plan be amended to provide that no person aged under 65 years should live in residential aged care by 2025.”⁷

- 11 The Commonwealth is committed to minimising the need for younger people to live in residential aged care. The guiding principles of the NDIS are set out in section 4 of the *National Disability Insurance Scheme Act 2013* (Cth) (**NDIS Act**), which includes a principle that people with disability have the same right as other members of Australian society to be able to determine their own best interests, including the right to exercise choice and control, and to engage as equal partners in decisions that will affect their lives, to the full extent of their capacity.⁸
- 12 The NDIS was designed in collaboration with people with disability who advocated for a scheme where individuals had choice and control over the supports they receive and choice and control over who provided those supports. The goals in the Action Plan reflect these important concepts of choice and control. They also reflect Article 19 of the United Nations convention on the rights of persons with disabilities (**Article 19**), which is in the following terms (emphasis added):

⁷ T5254: L15. See also T5250: L33.

⁸ Section 4(8) of the NDIS Act.

“Article 19 – Living independently and being included in the community

*States Parties to the present Convention recognise the equal right of all persons with disabilities to live in the community, with **choices** equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:*

- a) Persons with disabilities **have the opportunity to choose their place of residence** and where and with whom they live on an equal basis with others and are not obliged to live in a particular living arrangement;*
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;*
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.*

- 13 The Commonwealth agrees that residential aged care is not appropriate for younger people with disability and acknowledges the importance of SDA and alternative age appropriate forms of accommodation as important to people with disability exercising that choice and control. However, there are occasions where some participants may choose to continue to live in aged care. The story of Ms Robyn Spicer and her daughter, Jessie, is a good example of such a choice, a fact acknowledged by Counsel Assisting.⁹ Consequently, it would not be appropriate to amend the Action Plan targets to provide that no person aged under 65 years should live in residential aged care, as has been suggested by the Australian Human Rights Commission (**AHRC**). That categorical approach would be incongruent with Article 19.
- 14 There are two additional points to make about the AHRC’s recommendation:
- (a) The Commonwealth submits that rather than amending the Action Plan to provide (categorically) that no person aged under 65 years should live in residential aged care by 2025, the focus should be on achieving the goals and how to achieve the goals in the Action Plan, including by supporting the development of the SDA market so that young people with disability do have a real choice;
 - (b) There may be exceptional circumstances that mean a younger person has no other place to go and residential aged care provides a necessary safety net, even if only on a temporary basis.
- 15 This should not be taken to mean that the Commonwealth considers that residential aged care is anything other than a solution of last resort, or that the current numbers of YPIRAC are acceptable. The Commonwealth acknowledges that in many cases currently, younger people with disabilities in aged care do not have the opportunity to choose their place of residence and in this regard there is much work to be done. However, the matters set out above provide strong reasons why adopting the AHRC’s suggestion to amend the Action Plan is not necessary and indeed may, if implemented, be contrary to the guiding principles in the NDIS Act and Article 19 of choice and control.

⁹ T5247: L16.

D. PRIORITISING THE YPIRAC COHORT

"In 2019, much about the population of younger people in residential aged care remains unknown. This demonstrates that government has failed to prioritise younger people in aged care, despite policy rhetoric that it will do so."¹⁰

...

We heard that the current situation is the result of a complete lack of will by Government and that there is a real risk of history repeating itself in the nature of the 2006 initiative, which did very little, if anything, to resolve this issue"¹¹

- 16 Previous attempts by the Commonwealth to address the issue, such as the five-year initiative introduced by the Council of Australian Governments which ran from 2006 to 2011, only had the capacity to improve the circumstances of a small sample of the relevant population. Such schemes lacked the funding and policy structures on a scale essential to addressing the problem in a substantial and sustained way.
- 17 The introduction of the NDIS involved a profound shift in approach and policy capacity that was needed. As remarked by Mr Lye, there has not previously been *"a mechanism like the NDIS which is demand-driven and person-centred at our disposal to attack the problem"*.¹² The NDIS is a large and broad-ranging undertaking,¹³ and provides critical supports to YPIRAC who are eligible. The Commonwealth government has also specifically designed and introduced the Action Plan to focus the funding and support mechanisms which are available to address the needs of the YPIRAC cohort.
- 18 The Action Plan has a clearly defined objective of *"supporting those already living in aged care under 65 to find alternative, age appropriate housing and supports by 2025, if this is their goal"*.¹⁴ Work under the Action Plan is continuing, but important progress is underway or has already been completed, such as:
- (a) Development and implementation of a Project Plan and establishment of the Stakeholder Reference Group;
 - (b) The South Australian Hospital Discharge Pilot;¹⁵
 - (c) Roll out of the Complex Support Needs Pathway;¹⁶
 - (d) Agreement between the NDIS and health services to ensure that *"the NDIA and state and territory health departments will work together to develop aligned communications and guidance to support consistent implementation by both the NDIS and health systems"*;¹⁷ and

¹⁰ T5249:L4.

¹¹ T5253:L17.

¹² T4940:L24.

¹³ T5039: L11.

¹⁴ Tab 9 of the General Tender Bundle.

¹⁵ Tab 22 of the General Tender Bundle.

¹⁶ Tab 19 of the General Tender Bundle.

¹⁷ Tab 17 of the General Tender Bundle.

- (e) Establishment of the Hospital Discharge Framework to “guide the health systems and the National Disability Insurance Agency to ensure seamless and timely discharge for participants transitioning from hospital to a community-based setting with supports”.¹⁸
- 19 The Royal Commission should therefore not accept the submission by Counsel Assisting that there is “a complete lack of will by Government” to address the current situation has a rational evidentiary basis.¹⁹ The Commonwealth’s determination to seek to improve the accommodation and circumstances of young people who are presently in residential aged care, and who might be at risk of entering residential aged care, is substantive and demonstrable. It is an intent that is backed by a plan, targets, funding and an established methodology.
- 20 That is not to suggest that there are not important improvements that can and should be made, both in terms of timing and manner, to what is proposed and currently being implemented by the Commonwealth. However, it is not a fair characterisation that because there is scope to improve the current policy response there is no will on the part of the Commonwealth government to address the problem of YPIRAC.
- 21 The Royal Commission should consider the careful evidence given by Commonwealth witnesses setting out that which has been achieved, and acknowledging that which remains undone, in attempting to address this recognised problem. For example:
- (a) Dr Hartland stated that “*I think progress has certainly been slower than everybody would have wished for, but I think the policy response of creating an agency such as the NDIS that has the resources and the infrastructure set up to fully engage with young people is the right response, and we ... are now in quite a different situation, I think, than we’ve ever been in before in that we do actually have the institutional underpinnings to address this problem...*”²⁰
- (b) Mr Lye outlined that “*it’s not true to say that there’s not funding to achieve the plan. The NDIS is a demand-driven scheme. It’s about targeting that huge gun at the problem and so the money flows as we identify people in the – young people in the aged care population, we seek to get them into the Scheme and put the plans around them... And so it’s hugely important, the health interface and getting that issue of the supports that would give people the confidence to live in the community, to give them that confidence.*”²¹
- (c) Ms Rundle provided important context to the development of the NDIS in the face of the suggestion by Counsel Assisting that there was “decided” inaction by the Commonwealth:²²

“Well, I would say two things to that. One is there was no inaction; it just took a while. There was earlier action. So I think I’ve described that, in fact, the SDA was intended to be available for participants in transition from July of 2016. In the absence of the rule being developed, the then CEO issued a directive, a CEO directive, to try to enable planners to be able to put SDA into a participant’s plan – or the SDA supports into a participant’s plan for existing participants”

Ms Rundle’s evidence proceeded:

“it’s fair to say that there’s – that the experience of the scheme, a lot of this scheme, because it has never been done before in the world, is – a lot of it is experiential. There are things you

¹⁸ Tab 20 of the General Tender Bundle.

¹⁹ T5253 L18.

²⁰ T4879 L16.

²¹ T4963 L39.

²² T5060 L11.

learn along the way that you realise you could have done better. And definitely with SDA one of the things we learnt about SDA – it might have been plainly evident now to all of us that we should have agreed – should have put some things in the SDA rules earlier, but it wasn't evident at the time.”²³

- 22 While it is accepted, as was properly conceded by the relevant witnesses, that progress is not as uniformly advanced as might be wished, the evidence makes plain that there is a concerted and meaningful government effort in place to embed the funding and structures that will lead to those younger people in care who wish to leave doing so, and preventing others from entering aged care at all.

E. SPECIALIST DISABILITY ACCOMODATION

“Even of those that do, only 66 of them have SDA approved as part of their plan, 66. And, obviously, in respect of those 66 – they're still remaining in residential aged care at the present time.”²⁴

- 23 Specialist Disability Accommodation is an important element to the tools available in meeting the needs of young people in residential aged care. However, as the evidence makes clear, it is not the only mechanism by which those needs can be met.²⁵
- 24 Counsel Assisting referred more than once in closing submissions to there being only 66 people in residential aged care with SDA approved as part of their NDIS plan.²⁶ This was extracted from an earlier exchange with Ms Rundle, in which Counsel Assisting had asked for that specific figure.
- 25 In seeking to directly answer Counsel Assisting's question, Ms Rundle provided that datum, but added important qualifiers to it which were not reflected in Counsel Assisting's closing submissions. In particular, given the recent structural and rule changes around the SDA approval process, Ms Rundle stated that the reporting was “immature” and could not be “confidently” used.²⁷
- 26 Ms Rundle went on to add further detail, stating that:

“So it wasn't that we weren't looking for SDA properties before then because we were. We had a previous SDA rule. It just didn't allow us to put the SDA support in the person's plan until it identified a property. That was what changed in February. Prior to that, however, we used to add into people's plans, both in residential aged care settings and elsewhere. We had different names for this, but a common name was a housing options package where we would pay for assessments for that person's functional capability, so we understood what supports they might need in an accommodation setting and also we'd pay for support coordination and other supports to try and match them up to accommodation. So those things aren't captured in the data. All of that earlier effort and the fact that we were helping people weren't captured in the data. The – what we have done now is we've changed the rule so that it's a lot easier to capture in the data since, you know, February/March and it was, you know, after that time that we started doing the plans to be able to put those in.”²⁸

²³ T5060 L14.

²⁴ T5252:L23.

²⁵ T5054 L43 et seq.

²⁶ T5252 L23.

²⁷ T5055 L42; T5056 L9.

²⁸ T5056 L24.

- 27 Absent that context and detail, the reference to the “66 people” in Counsel Assisting’s closing submission was not reflective of the sum of the evidence, and risks mischaracterising the manner in which the need for SDA has been accounted for within NDIS procedures.
- 28 The current data systems used by the NDIA do not have the functionality to automatically record and collate those participants who have been specifically approved for SDA. Further, specific SDA data would not ordinarily be included in a participant’s plan unless their move into that approved SDA was imminent.
- 29 For those reasons, as made clear by Ms Rundle in her evidence, caution must attach to the use of, and any reliance on, that figure. While, in strict terms, it is the number currently available to the NDIA, given the limitations to the data it is unlikely to be reflective of the true number of younger participants in residential aged care for whom SDA provision, in some form, has been made.
- 30 It was also put to Ms Rundle that “*given the desirability of younger people not being in residential care, why isn’t it the case that all younger people in residential care automatically qualify for SDA?*”²⁹ There are sound reasons of policy and practice why that isn’t the case. In particular, two problems immediately present:
- (a) It is quite conceivable that SDA may not be the appropriate remedy or outcome for the participant in residential aged care. A home modification may be more efficient and practicable solution to enable the participant to live in a dwelling, location and community of their choice; and
 - (b) Blanket SDA approval would do very little to assist the participants practically and gives rise to the exact risks warned against by witnesses such as Dr Morkham.³⁰ SDA approval in isolation does not determine the type of SDA to be included in a participant’s plan, or the type of accommodation appropriate for that particular participant. That is the precise level of required detail that is obtained during the approval process, with the intent that any approval that might be given is specifically tailored to meeting the individual needs of that participant. It is this level of detail that will enable a developer to then construct appropriate SDA or for the market to otherwise respond accordingly.

²⁹ T 5053 L33.

³⁰ There is evidence before the Royal Commission that a truly functional SDA model requires, for example, “the young person and their family asked from the very get-go what it is they want, where do they want to live and how do they want to live”. See, in example, T5197 L 11, T5207 L35,