Submission to the Future reform – an integrated care at home program to support older Australians Discussion Paper

August 2017



## **About National Seniors Australia**

National Seniors Australia is a not-for-profit organisation that gives voice to issues that affect Australians aged 50 years and over. It is the largest membership organisation of its type in Australia with more than 200,000 members and is the fourth largest in the world.

- We give our members a voice we listen and represent our members' views to governments, business and the community on the issues of concern to the over 50s.
- We keep our members informed by providing news and information to our members through our Australia-wide branch network, comprehensive website, forums and meetings, bi-monthly lifestyle magazine and weekly e-newsletter.
- We provide a world of opportunity we offer members the chance to use their expertise, skills and life experience to make a difference by volunteering and making a difference to the lives of others.
- We help our members save we offer member rewards with discounts from thousands of businesses across Australia. We also offer exclusive travel discounts and more tours designed for the over 50s and provide our members with affordable, quality insurance to suit their needs.

## Contact

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## Introduction

National Seniors welcomes the opportunity to contribute to the development of an integrated care at home program to support older Australians.

The introduction of competition, choice and control in social care is one of the most significant reforms of welfare systems.

Many National Seniors members receive care or assistance in the home or have relatives or close friends who receive care or assistance in the home. Our members have a keen interest in ensuring that future direction of aged care maximises opportunities to remain in the home as they age by improving their access to reliable and high quality support and care.

This submission draws on feedback and comments from National Seniors members who generously shared their current experiences of care in the home. It also draws on evidence from the United Kingdom where the operation of individual budgets is well advanced.

National Seniors would like to thank all members who contributed to the development of this submission and looks forward to future opportunities to contribute consumer perspectives in ongoing debates about the future direction of care at home.

# Section 2. Reform context 2.3 Reforms to date

#### Comments

We would welcome your views and feedback on the February 2017 (*Increasing Choice*) reforms.

National Seniors has received limited feedback about the changes to home care from February 2017. It is likely that it is too soon for many consumers to fully understand the implications of the introduced changes. However, members have raised some concerns about the reforms.

Responses from National Seniors members have focused primarily on the increased costs resulting from the introduction of Consumer Directed Care (CDC). There has been criticism that the increased costs of care have resulted in reductions in care hours for care recipients. Concerns have also been raised about the greater burden on consumers and their carers from having to manage care arrangements under the CDC model.

This last issue is one that has been noted in the United Kingdom. It has been reported that consumers and carers experience increased psychological stress as a result of the increased responsibilities required to manage personal budgets.

#### Member Story #1 – cost increases lead to less services

"The CDC system is failing those who need it most. There is too much red tape and understanding the contract on the different packages is confusing. The administration fee has doubled in many cases and especially in level four packages where consumers have had to reduce the hours of the carer's visit so as to stay within the package budget level provided.

Admittedly service providers have extra paperwork since the CDC system started but the 'clients' should not have to bear the extra costs and cut down on the outside care they so desperately need to stay within the budget requirements

The client has to be diligent and check what is being charged and why. The whole idea of the CDC is to keep people in their homes as long as possible. When, a husband or wife is caring for their spouse, who may have dementia or other severe health disabilities, and they need help in managing the care, every bit of time allocated by outside help is needed to lighten the load.

To have to reduce the time means there is more pressure on the carer spouse which is detrimental to his/her health which eventually will result in not only one ill patient but two. Sometimes when there is a change of carer who does not know the routine, they have to be shown and this takes extra time on an already stretched time limit"

## Member Story #2 – impact of higher costs

"A dear family friend of mine who is a paraplegic and of sound mind was able to get by doing certain basic daily necessities, but had someone come in everyday to help him with medical requirements (e.g. change catheter, clean bed linen etc.). He complained that the cost had doubled since the CDC system started. He said he did not understand half the time what they were charging him for but assumed it was correct.

Recently he had a bad turn and ended up in ICU and was not expected to recover, but against all odds, did improve but it resulted in further deterioration of his health. He was in hospital for approximately 3-4 weeks and from there he found a place at a local aged care home. In the meantime, he has received a bill from his Service Provider for over \$1,000. Yet he has been in hospital most of the time.

At this stage he has lost his will to live and not interested in anything, but trying to get relief from his pain. I mentioned to him that he needed to get in touch with his service provider to find out what the bill entails. He just said he does not care anymore and is not going to do anything or pay anything.

#### Member Story #3 - impact of caring on carer health and wellbeing

"A member, whose wife has full blown dementia, is in a wheelchair and is 100 per cent reliant on her husband to care for her has been her full-time carer for the last 8-10 years. The husband is dedicated to her needs to make her life as comfortable as he can. While she looks so well and lives in her own world which no-one can enter, he is deteriorating with every year that goes by."

#### Member Story #4 – excessive administration fees

"In response to a call for members to submit observations, may I put it to you that the administration fees (under all guises of labelling e.g. monthly administration, scheduling etc.) are drawing up to, in my mother's case, 27 per cent of her and the Commonwealth's contributions to her home care each month.

It also appears the hourly rates are disproportionate to wages and are loaded also towards the supplier/coordination group, as well as charging an additional fee when that organisation has to outsource services."

## 3.1 Policy objectives

## Question

Are there any other key policy objectives that should be considered in a future care at home program?

National Seniors would suggest that the following policy objective be included to focus on the importance of dignity, respect and protection.

"Ensures consumers are treated with dignity and respect and protected from exploitation."

## Section 4. Reform options

## 4.2 An integrated assessment model

#### Question

What do you believe could be done to improve the current assessment arrangements, including addressing variations or different practices between programs or care types (e.g. residential care, home care and flexible care)?

National Seniors supports moving to an integrated assessment model for determining eligibility for aged care services. National Seniors supports calls for the integration of the Regional Assessment Process with the Aged Care Assessment Teams to deliver a coordinated team approach to assessment of needs.

National Seniors members have shared with us the importance of having flexible assessment processes that can readily and easily accommodate changes in function over time. Rather than having to undergo a whole new assessment when circumstances change, care recipients should be able to apply for further support and be assessed on the basis of changes to their level of need.

## Member Story #5 – need for flexible assessment process

"Found the system very good but long process first talking to Government then having an interview by Council each time we needed another category of help. Surely the one time would be sufficient then others would just be add-ons rather than going through all that process each time."

# **4.3.1 New higher level home care package** 4.3.2 Changing the current mix of home care packages

## Questions

Would you support the introduction of a new higher package level or other changes to the current package levels?

## If so, how might these reforms be funded within the existing aged care funding envelope?

National Seniors supports investigating whether a new higher level home care package is needed to provide more options to enable people to stay at home if they can. While a higher-level home care package may not be suitable for everyone as an alternative to residential care, it could help some people to stay at home if appropriate support was available.

There will need to be clear guidelines for the new higher level home care package to ensure that only those who would clearly benefit from this alternative arrangement have housing that is appropriate to cater for higher levels of need. It could be problematic if the home environment was not suitable to provide care for someone with high levels of need and support. As there would be a higher level of care required and this care would be costly it may be that the living arrangements of the care recipient will have an impact on the viability of a higherlevel home care package. Location of the home relative to services and other consumers is likely to be a major factor, in this regard. This would likely make it more difficult to offer higher level home care packages in rural or remote areas.

The package would need to be sufficiently funded to enable people to stay at home as an alternative to transferring to a residential care setting. Government should look at trialling a limited number of higher level home care packages to assess if these are suitable as an alternative to residential care in terms of cost and quality of care.

In theory, National Seniors supports the idea that funding for higher-level home care packages comes from existing residential care allocations foregone as a result of the introduction of a higher-level care package. As such, there must be evidence of a corresponding decrease in demand for residential care places for this to be justified. Taking away residential care places when there is unmet demand would be disastrous. As such, there must be adequate analysis undertaken to ensure that those who require residential care get access to this, if this is in their best interests and what they want.

## 4.4.1 Changing the current mix of individualised and block funding

#### Question

Which types of services might be best suited to different funding models, and why?

#### Question

What would be the impact on consumers and providers of moving to more individualised funding?

National Seniors members indicate to us that choice is a desirable characteristic of aged care services<sup>1</sup>. However, National Seniors would be concerned if an individual budget approach was the only option available to consumers receiving care at home.

National Seniors would argue there may be situations in which block funding is more advantageous to individualised budgets (and vice-versa).

Unfortunately, there is little evidence to show which situations where a consumer may be better or worse off under individualised or block funding.

While it is clear from the feedback from our members that there are situations where block funding is not be responsive to the needs of consumers (see member examples below), it is not clear if the reverse will be true under individualised funding.

Evidence from the United Kingdom<sup>2</sup> suggests that continuity, reliability, trust, mutual understanding and even friendship are important outcomes desired by older consumers. The

<sup>&</sup>lt;sup>1</sup> National Seniors 2017. Consumer Directed Care in Australia: Early state analysis and future directions. August 2017.

https://nationalseniors.com.au/system/files/08172617PAR\_ConsumerDirectedCare\_ResearchReport\_Web.pdf <sup>2</sup> Coventry University 2015. 'Social care packages: Coventry study shows direct payments do not guarantee choice and control for older people.' 4 February 2015. <u>http://www.coventry.ac.uk/primary-news/social-care-</u> packages-coventry-study-shows-direct-payments-do-not-guarantee-choice-and-control-for-older-people/

ability to have the same person coming at a regular time that is convenient to the consumer is important to consumers. This sentiment has been shared by members in feedback provided to National Seniors.

While personal budgets are designed to provide greater choice and control, it is important to understand that this control can be limited. Evidence from the UK shows, for example, that compromise and lack of choice still features among older people using personal budgets, regardless of whether they are managed or involve a direct payment<sup>3</sup>.

Consumers who have a bad experience of a provider under a block funding arrangement, because they are not able to have the same person, who turns up regularly at times that are convenient to the consumer, may find that some of these problems persist under an individualised funding model.

Choice and control issues may be exaggerated in areas where service providers struggle to maintain an effective presence, such as in rural, regional and remote communities.

In this regard, we should be realistic about the promise individualised funding to meet the expectations of consumers and be prepared to utilise whichever funding model best meets the needs of consumers.

## Member Story #6 – Poor communication and coordination

"We have had house cleaning for the past four years. We have had some good and some bad cleaners. One of the biggest problems we have experienced is communication from the organisation - they have a set of rules they expect you to follow but little about their obligations to the client.

Another problem is the different cleaners that come and who demand different tools and cleaning agents. At times no one turns up because of staff issues but then they turn up the next day unannounced when you have your spouse at a doctor's visit and the organisation turns the table on you.

I believe our local agency has become too big and has too many chiefs on big wages and are more interested in themselves rather than the service they should be providing. We have thought very seriously of cancelling our service and struggling on our own. Hopefully the review give the client more control over the services provided."

#### Member Story #7 – Lack of appropriate staff

"Over the period 2011 to 2014 I cared for my dying husband at home. He had bone cancer which went to his organs and was in constant pain. A provider was nominated to provide assistance and visited once a week. I was also provided with one hour cleaning service, per week. This was because I had back surgery.

<sup>&</sup>lt;sup>3</sup> Woolham, J. 2012. 'Are Personal Budgets the best way of delivering personalised social care to older people?' http://ssrg.org.uk/wp-content/uploads/2012/01/John\_woolham.pdf

The care we received was less than adequate given that the last 12 months my husband had to use a wheelchair. He was very determined and knew if he couldn't get into the chair, I could not lift him.

I finally rang the supervisor, as I had requested more help and had not received a reply. She visited and immediately rang a hospice and ambulance. My husband passed away five days later.

I would like to think that future cases receive more assistance, particularly from trained male nurses. When my husband went into the hospice they rostered men to assist as he was a tall, big boned man.

I found the nurses visiting each week did not help. They even asked for letters each week from the doctor to give injections. Finally, a doctor living nearby told them he would give the daily injections."

#### Question

Are there other ways of funding particular services or assisting consumers with lower care or support needs, e.g. a combination of individualised funding and block funding, vouchers etc.?

There may be scope for certain services currently delivered under block funding to be funded differently.

For example, home help type services, such as mowing, maintenance or cleaning, could be funded by providing a direct payment to the consumer who could use this funding to contract an appropriate person. This would require a means to ensure that the funding is used to hire approved contractors to reduce the risk of misuse and exploitation.

Private operators e.g. mowing contractors and cleaners, could register to deliver approved services. To be approved they should undergo appropriate vetting e.g. police checks, and be required to participate in an online advisor rating system (trip advisor style) to enable consumer feedback.

This is important because National Seniors members have shared with us stories of situations where the conduct of care staff has been questionable. We have heard, for example, of instances where items have been stolen by a care worker.

Consumers could be issued with vouchers or smartcards to facilitate payment to approved providers.

A system of oversight and crosschecking would be required including a regime of spot checks to ensure that vulnerable consumers were receiving the services requested and were not subject to abuse or exploitation from contractors.

Contractors could, for example, utilise smartphones to record before and after photographs of services rendered. This would have the benefit of providing a log of when someone arrived and left, ensuring transparency in the delivery of services using individual contractors.

Greater flexibility should also be afforded to consumers with regard to the types of approved activities to ensure that they are being assisted with tasks they require help with. National Seniors has heard from members that they are often not able to get help with more difficult and irregular tasks, because these are not allowed under current rules.

There is also a need to better communicate which services are available so there is no confusion about what support can be received.

## Member Story #8 – flexible funding rules

"Most pensioners will need more help than is provided in the available packages, e.g. for house cleaning, gardening, etc. We were told that one provider offers services as required, e.g. gutter cleaning so much, house cleaning so much, etc. However, this sort of assistance is not widely available and it would be very useful."

## Member Story #9 – flexible funding rules

"At this stage, our needs are somebody to vacuum clean the carpet every three weeks, minor maintenance, such as changing light bulbs, and minor repairs as required. Whilst we hire somebody to do the mowing, we still need occasional trimming shrubs and weeding. To summarize, we do need for someone to help us every three of four weeks."

#### Member story #10 - timing inconsistencies

"I glanced at the clock as they arrived just before 2.00pm. Two people for an hour each; two hours equivalence. I explained what I wanted done, and at 2.25 pm, they told me they had done as much as they could, and that they had arrived much earlier than I thought I remembered."

## 4.5.1 Refocussing assessment and referral for services

## Questions

Should consumers receive short-term intensive restorative/reablement interventions before the need for ongoing support is assessed?

## If so, what considerations need to be taken into account with this approach?

While short-term intensive restorative/reablement interventions may help to arrest and reverse functional decline, it is possible that an episode requiring a short-term intensive restorative/reablement intervention occurs as a direct result of functional decline combined with inadequate access to support. In such cases, it would be detrimental to neglect assessment of whether ongoing support is required by an individual.

Consumers should not blanketly be required to receive short-term intensive restorative/reablement interventions before being assessed for ongoing support. They should undergo assessment to ensure that they do not have an underlying need for ongoing support. If there is a need to reassess eligibility for ongoing support because of a likelihood of improved functioning, this should occur as required.

Ideally, assessment should be looking for opportunities to support reablement through incidental activities and factor these into a support package. It could be that consumers are encouraged to use a proportion of their ongoing support package to fund activities that promote reablement, if appropriate.

As our members point out, it is possible that the mere act of receiving some ongoing support has immeasurable wellbeing impacts on care recipient, which should not be underestimated.

## Member Story #11 – wellbeing impact of assistance

"I can only relate to the subject from "experience" when my mother was alive and living in NSW. Home care used to give her a reason to get up on that day. She might have spent the day before "cleaning up" for her home care lady, but it gave her something to do and, of course, someone to talk to on the day. I hope that my husband and I will be able to have the same thing here in Tasmania when the time comes."

#### Question

How could a wellness and independence focus be better embedded throughout the various stages of the consumer journey (i.e. from initial contact with My Aged Care through to service delivery)?

Greater emphasis needs to be placed on funding activities that consumers require support with so that consumers can be left to continue activities which they are capable of and which passively contribute to reablement and ongoing independence.

As feedback from one member shows, there are difficulties gaining access to the right kind of assistance. Activities that are covered by the Commonwealth Home Support Program could be readily undertaken by the care recipient, whereas activities that are not readily undertaken by the recipient (and may be unsafe) are not able to be supported.

This is problematic not only because it is undermining the capacity of the program to promote independence but because it takes away the very tasks that may be beneficial to a care recipient – ones that may promote physical activity and exercise, and promote mental and physical wellbeing.

## Member Story #12 - incidental exercise

"In March 2016, I first made an application for assistance with 'home maintenance'. I received an aged care number at that time. I first tried to get assistance with lopping a tree on my property; and with 'regular pruning of a hedge', in January 2017.

I found there was no provider who could help with the 'tree lopping'; and it took me until June 2017 before a service provider finally turned up to help with the hedge. Most of the providers are equipped to do 'lawn mowing' but little else. Personally, I am okay to do my own lawn mowing. it provides me with an opportunity to be active and exercise. It is the more strenuous, non-routine and or emergency, (storm damage), tasks that I am looking for assistance with. However, I found that the services currently funded / listed are very few and rather basic."

## 4.6.1 Ensuring that services are responsive to consumer needs and maximise independence

#### Questions

How do we ensure that funding is being used effectively to maximise a person's ability to live in the community and to delay entry to residential care for as long as possible? <u>For example</u>, should funding be targeted to services or activities where there is a stronger connection with care and/or independent living? Are there examples of current services or activities that you believe should not be funded by government?

Ultimately, the test of whether an activity should be funded by government is whether it assists a consumer to maintain their independence and contributes to their wellbeing.

This can only be achieved by making a proper assessment with the consumer about their situation and needs. If a consumer is eligible for support they should be active in determining the type of support they need.

## 4.8.2 Supporting informed choice for consumers who may require additional support

#### Question

What additional supports could be considered to ensure that people with diverse needs can access services and make informed choices and exercise control over their care?

What is required are care navigators who work with the care recipient to identify activities required. This is something that has been raised on numerous occasions by National Seniors members.

Our members have shared with us their experience of having to assist others, particularly those from a Culturally and Linguistically Diverse background who do not speak English as a first language. These members can spend two to three hours assisting them to identify the assistance they require.

Navigators could help to develop a plan outlining the care and support required. Navigators would act to assist a consumer if they were encountering problems with care or assistance provided. Periodic review of care arrangements by the Navigator would determine if the suite of activities utilised provide effective and adequate support for the consumer. Navigators could also be paid on an outcome basis to ensure that they are assisting a consumer to access activities that are beneficial to their health and wellbeing.

Research in the United Kingdom has shown that recipients of individualised funding require assistance to help them to develop care plans<sup>4</sup>.

"older people living with multiple and often complex needs may be better served by a 'right' of access to skilled professional support from a gerontology specialist, able to work with them to 'co-produce' person-centred care and support. This different process would require advice giving, empathy and support over a longer period than usually possible currently in most operational social care settings, but there is some evidence of better, more sustainable and effective outcomes in the longer term"

## Member Story #13 – lack of support

"My mother had an ACAT assessment last year and she is a level four. No suggestions were provided other than that she was told she qualified for some hours in home assistance. The problem is that we have no idea where to get this assistance, and how it is funded. We have no contact person to guide us so we are left to our own resources so things go on as usual... There is nobody to advise us. My Aged Care is a call centre which just gives you reference numbers!"

## Member Story #14 – lack of support

"I am taking this opportunity to feed back to you a friend's negative experience with home care services She is 85 and had heart surgery many months ago, so was assessed as entitled to home care. In spite of the assessment she has heard nothing further, in spite of making phone calls."

## 4.10 Other suggestions for reform

#### Question

Do you have other suggestions for care at home reform, or views on how changes might be progressively introduced or sequenced?

National Seniors has been alerted to a number of instances where the occupational health and safety laws undermine the effectiveness of the system to provide support to older people, which may be of interest.

## Member Story #15 - occupational health and safety

"We have tried out the home cleaning package of home care for elderly people. As far as we are concerned, it is not worth even the small amount paid to the supplier because the occupational health regulations prevent the cleaner shifting even a chair, or lifting anything above shoulder height. As such, we have to move or lower any object where we want the floor or shelf cleaned. We might as well do the job ourselves. After a two-month trial, we ceased the help."

<sup>&</sup>lt;sup>4</sup> Woolham, J., Daly, G., Sparks, T., Ritters, K and Steils, N. 2017. 'Do direct payments improve outcomes for older people who receive social care? Differences in outcome between people aged 75+ who have a managed personal budget or a direct payment.' in Ageing and Society, 37, 5, May 2017, pp. 961-984.

#### Member Story #16 – occupational health and safety

"As a receiver of community care, to have my floor cleaned and to scrub the shower recess, the people who perform the service are great people however and do their duties according to the agreement with the company. However, the cleaning of the shower recess involves a quick scrub of the shower screen and a lick of the mop over the recess floor. This is a safety issue, as with the build-up of soap scum and body grease, makes the shower floor very slippery. Voicing my concerns with another from the nursing profession, I was told that no service provider would scrub the floor of the shower. What about those people that are older, more frail people than myself who shower and whether they stand or sit, there is still the process of getting into the shower.

My issue is, my disability makes it very hard for me to clean the shower recess yet I scrub the recess floor myself with a brush and strong cleaner. The reason why the service was approached in the first place was to scrub the floor of the shower.

As mentioned, the service provided by the workers is great however the service provider needs to look at the actual way things are cleaned mainly for safety reasons."