The future of self-management: our decision

Workshop Report

December 2022

Contents

Background

The Royal Commission into Aged Care Quality and Safety released its final report "Care, Dignity and Respect" in 2021. Several recommendations in that report were targeted at changing the way Home Care was delivered. It came at a time when changes to Home Care were already being considered by the then government.

Recommendation 35: Care at Home category reflected the Commonwealth's plans to merge the Commonwealth Home Support Program (CHSP) and Home Care Packages (HCP) Program. A more streamlined program of care at home was aimed at making the system easier to navigate, particularly as an individual's needs change and increase.

OPAN welcomed the proposed move to a model of funding based on individually assessed need. This will help ensure that the level of care provided to an individual in their home and community is not limited to a capped package of funding. We firmly believe that this type of funding model will only be successful if it is supported by a well-resourced, highly skilled, and independent assessment workforce.

Recommendation 35 and *Recommendation 36: Care at home to include allied health care* aimed to improve access to allied health, restorative care, palliative and end-of-life care. OPAN considers access to both ongoing and episodic allied health care as critical in supporting older people to maintain their independence, functional wellbeing, and quality of life. OPAN notes pricing for allied health care under the NDIS is currently set at a higher rate than in aged care. NDIS pricing will need to be taken into consideration to ensure that the allied health workforce is accessible within the aged care system for older people living in their own homes and in residential aged care.

OPAN supports respite care, social support, assistive technologies and home modifications being in separate funding categories to the general Care at Home category. These services can be costly and in the current Home Care Package system, older people must often reduce the frequency of their regular direct care supports to save package funds for access to these more intermittent services. We also note these types of services require capital investment and flexibility to be sustainable and support a grant funding approach for these categories.

We note the Royal Commission has suggested this new Care at Home category should be developed and iteratively refined in consultation with the aged care sector and older people. OPAN maintains that older people should not just be consulted on the new Care at Home category. Older people with lived experience receiving care at home should be actively participating in the co-design of this new program of care.

OPAN was and remains extremely disappointed that the Royal Commission's Care at Home model did not actively support older people to self-manage their care at home. OPAN is particularly concerned that *Recommendation 31 - Approved provider's responsibility for care management* imposes an expectation that older people receiving care at home must select a lead provider to administer and coordinate their supports and care.

The right to self-manage

OPAN's position is that no-one is better placed to understand the needs and wants of an older person, than the older person themselves. Not acknowledging and respecting an older person's right to self-determination and the capacity of many older people to self-manage their care and care funding is ageism in action. OPAN maintains that the starting point for care at home should be for every older person to be able to self-manage with the option of seeking a care manager if they wish.

Older people, their carers and families are increasingly voicing their concerns over the lack of control they have over their home care packages. Many are seeking more control over the use of package funds, the types of services they receive, when they receive services, who delivers the services, which goods and equipment fit the individual's needs best (and where to source them at the right price) with ready access to assistance if needed. OPAN does not want to see these issues and concerns replicated in the new in-home aged care program.

Older people should have a right to self-manage and this option should be included within the spectrum of program delivery from full self-management, to partial self-management, to provider management (done in partnership with the older person). This will ensure varying levels of choice and control for the older person, as directed by the older person. The underlying principle is that older people, and their carers, best understand their own needs and must be empowered to direct their care to meet those needs. This approach recognises that older people have been making decisions about

their care and services their whole life and should continue to be able to do so. Flexible support, planning, training and checking in may be required but this should always seek to enable ongoing autonomy and maximise self-agency.

Flexibility of self-management options

Older people have noted that self-management is not 'one size fits all' and must include a range of flexible options. Some older people will choose to fully self-manage, determining what services they receive, when and by whom and managing the funding allocated to their care. Alternatively, a person could choose to partially self-manage. That is, they could have choice and control over staffing, but a provider of their choice handles the financial side, or alternatively the provider is responsible for hiring staff at the older person's request, but the older person is responsible for managing everything else.

In some circumstances, older people may choose to self-manage after being assessed as not having the capability to do so. Options of support must be available for people who need assistance to self-manage, rather than a blanket refusal, alongside protections for people whom self-management has been mutually agreed as not suitable.

The option to self-manage must be actively promoted and a range of accessible resources should be made available to support people on their self-management journey. Resources must include access to clear, detailed, and independent information on the range of supports that can be accessed. In addition, clear and efficient payment systems must be in place so that older people who self-manage are not out of pocket.

Acknowledgements

OPAN acknowledges the lived experience and wisdom of Lesley Forster, Mona Orszulak and Stella Perkins in co-designing the consultation.

Introduction

"Now that I'm self-managed, I can at least find the right support workers, form a rapport and feel comfortable and confident of their good service as I'm regarded as the person who makes the decision about whether to keep their services or discontinue them, and feel that the very person who is providing me with the support I need is getting fair remuneration. The fact that I'm regarded as a client who has individual preferences such as the time to be showered and fed, waking up, going to bed, is the most important factor for my choice and control with self-management. I feel like a human being not just a number on a roster!"

In response to the Royal Commission *Recommendations 35 and 118*, the Australian Government committed to introducing a new model of aged care at home. The new program will replace the existing Commonwealth Home Support Program (CHSP), Home Care Packages (HCP) Program and the Short-Term Restorative Care (STRC) Program.

In December 2021 the Department of Health released a paper "Support at Home Program Overview". It included design features in support of self-management:

"The new regulatory model under the Support at Home Program would enable clients to self-manage their care, including by using multiple service providers if they choose to do so."

"Self-management under Support at Home would be enabled by a new ICT payments platform which would allow senior Australians and providers to view the person's entitlements and book and pay for services at the point of delivery."

Following a change of government, the implementation timeframe for the new program returned to that originally proposed by the Royal Commission. In October 2022 a discussion paper was released, canvassing key areas for the design of a new in-home aged care program including how self-management across multiple providers would operate in practice. The consultation questions included:

"Should the older Australians be responsible for managing their own budget and ensuring they stay within their funding entitlements? How might this work?"

In both papers, self-management is focused on the ability to choose multiple providers for different services rather than having one lead provider as recommended by the Royal Commission.

Older people have repeatedly advocated for more choice, control and flexibility in managing aged care services at home. While many older people would like to have one service provider to coordinate and manage their care at home, others have told us that far from providers delivering consumer-directed care, they feel they are receiving provider-directed care.

The need for older people to track their home care budget to ensure they don't over-book services should not be a barrier to self-management. Third-party financial intermediaries and real-time payment platforms could be utilised to avoid care plans exceeding budget and to facilitate access to contingency funds for short-term increases in service. If the choice to use different providers of services to meet individual needs was made easier for older people, it is likely that a greater proportion would be willing to self-manage their care. This would also enable better use of care management resources at the times that it is required and for older people that need it most.

OPAN does not believe that the level of choice and control sought by older people has been fully captured in the design of the new in-home aged care program.

OPAN recommends that the Department of Health and Aged Care work with older people to further explore and design this option.

Included and excluded goods and services

The top presenting issues in advocacy casework with older people receiving Home Care Packages is the application of the Inclusion and Exclusions Framework. The Operational Manual recommends that where a care or service type is not specified in the inclusions and exclusions list, providers and care recipients should work in partnership to determine if the service, support, or purchase:

- is directly linked to identified care needs and goals
- will optimise health and wellbeing
- is necessary to support the care recipient to remain living safely and independently in their home

- can be delivered within the available package budget
- would be considered an acceptable use of Government funds.

Advocates play an important role in reminding providers of the importance of working through the Framework with clients when making decisions about items not specifically listed as an included or excluded item. Advocates have observed providers using the Inclusions and Exclusions Framework to the detriment of the older person, in some instances, prioritising value for money over the clients' individual goals and overall wellbeing. In other instances, providers insist on duplicating health professional assessments for high-cost items, requiring costly health professional assessments for purchases of low cost and low-risk items or that items must be purchased from their preferred provider at a higher price.

Excluded items case example

A client sought advocacy support when her Home Care Package provider declined to approve purchase of a microwave oven. The client has severe arthritis and uses heat to manage the pain. The client had been using a hot water bottle to provide relief, but their physiotherapist identified this to be a burns risk and recommended use of a microwave to minimise the risk. Following continued denial of the purchase by the provider, the client lodged a complaint with the Aged Care Quality and Safety Commission. The initial receiving officer did not accept the complaint, advising it was clear the item requested was excluded and should be purchased by the client from their own income. The client requested a review of the Commission's decision. After eight months, the provider and Commission determined that all the alternative heat sources explored were not acceptable due to burns risk to the client, and it was agreed that the purchase of a microwave would be a relevant use of HCP funds in this circumstance.

OPAN acknowledges there are many requests made for items, services and supports that are not considered the responsibility of the Department of Health and Aged Care. OPAN is concerned that gaps in the broader health, housing and social service systems means that older people often do not have access to timely and viable alternative options through other Commonwealth, State or Territory funded programs. OPAN has observed how these service system gaps impact on the health and wellbeing of older people and reduce their ability to remain living independently in their own home.

Individuals experiencing financial hardship, unable to self-fund essential items, are often impacted the most.

OPAN recommends the design of the new in-home program should be informed by mapping trends in Home Care Package excluded item requests against the availability of other funded programs. A mapping exercise of this nature would assist in identifying gaps in supports and inform the future planning of initiatives to support older people to remain living at home for longer. OPAN recognises the importance of a sustainable and cost-effective home care system with appropriate, checks, authorisations and controls. However, OPAN continues to advocate that there is scope for nuance and re-evaluation.

These examples of drawn-out negotiations with providers, or of providers refusing to negotiate, confirm for many older people that self-management will provide the best outcome for them. OPAN acknowledges that home modifications and goods, equipment and assistive technology (GEAT) will be a separately funded program to other supports in the new in-home care program. It is imperative that this sub-program is also co-designed with older people to prevent the current situation continuing.

A future home care program should have a simple and fast mechanism to enable purchase of low-risk items and items recommended by health professionals to support older people's safety and wellbeing at home. The ability for an older person to request a senior advocate to review an excluded item, where there is an impact on personal wellbeing, also needs to be established in the new in-home care program.

Consultation co-designed with older people with experience of self-management

In response to concerns about the future of self-management in the new program, OPAN worked with members of the National Older Persons Reference Group (NOPRG) who self-manage and who facilitate an online self-management support group to plan a more extensive consultation.

As part of this consultation OPAN ran a survey to identify the key themes/issues that are important to people who currently self-manage that they would like to see addressed in the new in-home aged care program.

Survey

An online survey was developed and circulated which had over 350 responses. These were used to inform the agenda for a consultation workshop agenda and to further shape self-management concepts. 190 of the people responding to the online survey currently self-manage their care. They described the following benefits of self-managing their care and services.

Flexibility, choice and control about when, where and how I receive care

Self-management gives flexibility, choice and control about when, where and how the person receives care. This included choice and control over who provided care and supports, when the care and supports were provided and what care and supports were provided. Respondents noted:

- "Self-management provides me with choice and control over who, when and what I need, not just to accommodate the managing provider's business model."

- "I like to choose the services and products that suit my needs. Not one size fits all."

- "More choice and improved capacity to find the services or supports that best meet my needs."

Personalised services, tailored to my needs, goals and preferences – because I know what I need best

A more personalised service, tailored to the older person's needs, goals and preferences as older people know what their needs are and the best way to meet them. respondents noted:

- "I know better than others what my needs are."

- "[I] have [the] best understanding of my partner's needs; what matters to him, how to actively and creatively engage him to live well and remain connected to

family, friends, peers and community. It [self-management] gives [me] more control/choice of contracted services, and importantly, better value for money."

- "Because I want control, and I don't want to be 'managed'."

Dignity, independence and autonomy

Dignity, independence, and autonomy as older people can manage their own affairs and the care they need and want to retain their independence. Respondents noted:

- " I am quite capable of deciding what my support needs are."

- "I want to make my own decisions about care and what we need."

- " I am capable of managing my own affairs!"

- "Self-management is vastly superior in its provision of autonomy, choice and control across every aspect of home care."

- "Greater dignity and control for my mother. She has no idea how self-management works, but I guide her through. She selects people she likes, her relationship with her workers is number one to her. An efficient service provider is essential to keep things moving for me as the daughter managing the package."

Choosing workers based on rapport

Older people want choice over who comes into their home, when they come and what tasks they perform. Choosing workers based on rapport, and not having constantly changing workers is very important. (Noting that workers must be suitably qualified for the service they are providing e.g., RNs, allied health practitioners etc.) Respondents noted:

- "I want to choose my workers, and the times they work, and their duties."

- "To have the free choice of workers suitable to my needs...to be able to vet said workers, and to ensure consistency with the days and times of day they work for me. Having things changed at the whim of a provider at short notice is very distressing for a person living with dementia, and providers do not 'get' that."

- "To ensure that we have reliable staff. With previous providers they have no staff and then we have no service."

- "Build a relationship with [the] same support person, not a different one each time."

- "I enjoy autonomy over who my support workers are, what duties they carry out, how often they attend and for how long. I decide what tradespeople attend to modifications. I decide where I purchase items from."

Saving money on fees

Older people considered self-management better value as it enables saving money on fees and allows more choice and control.

- "It's better value."

- "The rates charged by organisations to manage my package is far too high."

- "I can get more hours by self-managing, there are fewer problems, can choose who comes into my home to help me out."

- "I need the extra funding for myself and not giving to providers."

- "Managed providers take an exorbitant amount, and you really don't get a say in who they send as support workers or when they come. There is always an added cost to the amount paid the support worker taken from the funding and sometimes it is 100 per cent more."

- "Save money. Have choice. Avoid second rate providers (have previous experience)."

- "I like that there is more of my funding for meeting my needs because my provider fees are a flat rate percentage of the funds and no more."

It should be noted here that often, when discussions on self-management are occurring, it is argued by those who are not supportive of self-management, that the only reason people want to self-manage is to save money. However, the survey, and the consultation, demonstrated that the prime reason people self-manage is to maintain the choice and control that they have had throughout their lives.

Following the survey, in November 2022 OPAN hosted a consultation workshop with older people who self-manage their home care to further explore what they want from the new in-home aged care program. The goal was to discuss the benefits and challenges of self-management and focus on how it could work as part of the new in-

home care program. It was acknowledged there is still a lot of uncertainty about program design and significant demand for information about the new program. The workshop focused on the key benefits and challenges of self-management and will inform further webinars and future consultation.

Workshop

The purpose of the workshop was to hear directly from older people about self-management to inform the development of the new in-home care program. As part of the consultation, OPAN sought to:

- develop a common understanding of self-management

- understand the benefits of self-management and the challenges

- consider how self-management could work as part of the new in-home care program.

A consultant was engaged to facilitate the online workshop and to formulate further recommendations for the Department of Health and Aged Care to consider. Representatives from the Department were in attendance and were able to hear directly from older people about self-management, why people self-manage and what is needed into the future. They were also able to ask additional questions of participants.

What is self-management?

Workshop participants acknowledged Council of the Aged (COTA) and the Department of Health and Aged Care both have definitions and descriptions of self-management. Lesley and Mona shared their perspectives and those of members of the group they facilitate. In summary self-management means:

- choice and control over which care and services are received

- choice and control over when care and services are delivered

- choice and control over where and how the funding is utilised.

Flexibility was frequently mentioned - in providing services when needed on a convenient day and time along with the flexibility to change arrangements made between the recipient and support provider. Participants did not want to have to go through a provider or care manager and experience delays in the timeliness of the service. Many older people need to have a service provided more urgently or more frequently and this should be able to be negotiated directly without having to seek

permission from the aged care provider, providing the service is within time and funding allowances.

Choice and control are paramount for older people receiving home care packages. Self-management enables this. The older person can determine how best to utilise the funding that is provided and the hours of care that are allocated to address their needs. This may include making choices that involve personal risk. Participants felt self-management of home care is the most consumer-centric model and that the Charter of Aged Care Rights should drive all decisions about access to care and services.

Workshop participants valued autonomy and independence to build a sense of agency and self-esteem which produces feelings of wellbeing. It was reiterated that it is a basic right to make decisions about one's own life. Participants derived a high level of satisfaction of getting value for money and achieving set goals.

What is and is not working well with self-management?

Workshop participants shared their thoughts on what self-management means to them and what is and is not working.

The self-management continuum

Self-management works well now for some. A current approach for one recipient involves sending all receipts and invoices to accounts for reimbursement and this was regarded as easy. It was noted that definitions of self-management should include what an individual home care recipient's level of comfort with risk is, as risk is often used as a reason why providers do not support self-management. Older people want the flexibility to choose suppliers, care managers and support people and not just be informed of who they are. They query the value of the current approved provider model to older people versus the value to government. Some do not want control of the whole package and are happy for a provider to control payment and compliance issues.

Self-management should not be 'one way'. It should be person-centred. There should be more than one way of doing things which is centred around the individual rather

than older people being tied down to a specific model. Partial self-management needs to be an option, particularly for people who have informal support around them and want some choice and control. Home care recipients should be able to choose who provides care and when it occurs. They need to be able to directly contact the people caring for them, without having to communicate via a provider. Importantly self-management has offered stability in care workers not experienced in provider - managed care. Home care recipients also need the choice of being able to select and pay for products rather than using products solely selected by providers. An example was that continence products from supermarkets can be cheaper and more suitable than those available through providers.

The difference between how self-management operates in the National Disability Insurance Scheme (NDIS) and in aged care was a source of confusion as both systems operate differently. While this consultation is focused on aged care, it was discussed that self-management in the current system is equivalent to 'plan management' in the NDIS. Terminology around self-management needs to be clarified and awareness of what self-management means needs to increase. There is significant demand for full self-management of all support and funding versus self-management of multiple service providers.

Some participants felt that, after eligibility and means testing, individuals should be allowed to have full control of the funds allocated to their care and support.

Quality concerns

It was noted there are significant differences in package management and care management fees charged by different providers for similar models of self-management (for example there is a range of between 33% and 13%). Older people must spend time learning the system to achieve desired results. The My Aged Care website does not identify providers who offer self-management and there are not enough 'true' self-managed providers.

Participants acknowledged that while there are many providers to choose from, they believed that not all providers were suitable to meet their needs. In addition, they felt that many providers did not have enough appropriately qualified people on staff. They also felt that people with low-level qualifications undertaking assessments was inappropriate and dangerous. For successful self-management, older people need to

be empowered to choose the best provider for them and change providers when necessary. Without a client-centred provider, older people cannot receive the best outcome. Participants felt there needs to be a review of the guidelines and expectations of quality standards for providers, with some 'old school' providers who do not really offer self-management yet charge the same fees needing to be removed as approved providers.

Participants reported they sometimes had low expectations of providers and they experienced obstacles in care from inconsistencies in what is approved and not approved. Older people have experienced waiting for an unreasonable amount of time for a provider to respond to a client request/phone call/communication. Some found communication from providers to be disrespectful and verging on bullying and intimidation, impacting the mental health of participants. They wanted providers to assume in the first instance, that older people have the capacity to self-manage and the right to be treated with dignity and respect.

An example was shared of inadequate communication when the provider chose to terminate services. When the provider could not explain why services were terminated, they made a false allegation of abuse. The degree of power imbalance between providers and consumers is seen as unacceptable.

Support to self-manage

It was noted that there is a need for independent care partners when and if necessary to come in at specific times or in an emergency to offer support. It was emphasised that care partners must be independent of providers. An example was shared of a recipient who mismanaged funds to the point that the individual was in significant debt. There is value in a third party that is independent and can be a mentor or monitor. Self-management is not easy and cannot be done by everyone. However, there was agreement that everyone should have the opportunity. Some would like the option of nominating someone from within their own life as a care partner (e.g. a spouse or adult child). They felt that if someone was already the nominated or authorised representative, they should be recognised as a care partner.

Technology could help to improve self-management, however, there needs to be ongoing technology training and accessible support available. Providers that have online platforms are looking to meet reporting requirements they expect will be

introduced. Technology is being explored to meet these requirements. What needs to be clear is that some companies are already putting this in place and improving it. Care plans need to be made readily available to older people and carers. It is vital that individuals are actively engaged with care plan development and that they have real time access to these, along with any case notes or reports made about them. The right of an individual to their privacy is critical as is the ability for the recipient to read in real time any comments being made. Data security around this is important.

There was support for sharing of information across multiple paid care workers and family carers, where the consent/agreement of the recipient is provided. Some also felt this should include guidance from GPs and specialists where necessary and with consent.

In response to a question about whether there is a plan for a real time My Aged Care portal, it was noted the Department is considering a range of options as they consult on what the new program will look like.

Relationships between providers and consumers

There is significant value in self-management as it gives choice, freedom, reduced fees, autonomy, independence, decision-making capacity and continuity of workers. What good self-management looks like is different to everyone. Some want to look at invoices, some do not, some want a partial care manager, some want to manage some reporting. Tasks of self-management differ based on capacity, willingness and ability. One model will not work. It needs to be different for different people.

With some feedback specific to self-management and some relevant to provider conduct, participants wanted to avoid the judgement of a provider or being pitted against the provider over inclusions and exclusions. Participants did not want providers to act as gatekeepers or obstacles. They did not want the confusion of hidden, excessive, or unwarranted fees and charges. Participants did not want to feel they were being treated like a child or a problem, or in a disrespectful manner.

Participants wanted the new program to address the power imbalance between older people receiving home care and providers. They wanted to be able to change the power dynamic to have more power to overcome the common experience of paternalism and ageism. They wanted consistency and clarity in what is approved, flexibility, in what services are provided and when they are received to reflect changing

needs. Participants wanted access to important information about themselves and their services and for a care recipient to be able to direct effective communication around their care and support network without raising privacy issues. They want to be responded to in a timely way, to be treated with dignity and respect, and to remain in control of their lives.

Co-design across the aged care system

Participants wanted choice and control at a broader and deeper level as well. Some felt the program design being presented by government reflected decisions that have already been made. Others felt older people are being listened to and expressed appreciation for the engagement opportunities. However, many people are worried about what is planned, and they want to co-design the new program.

It was acknowledged the Aged Care Quality Standards will feed into the program changes that are occurring. It was noted the pilot of the new home care assessment and classification framework has not yet commenced. Participants wanted self-management of home care to be included as a key feature of the pilot. They also felt there is a need to educate the Aged Care Quality and Safety Commission about self-management, with the example given of the Commission staff speaking to a home care recipient and wanting to understand how they know their care workers are performing. They then wanted to speak to the care workers directly instead of listening to advice from the recipient.

What is needed for effective self-management moving forward?

Care partners

It was noted some of the critical concepts identified include an independent care manager/care partner who can be available at specific times or at the request of a person receiving home care. The group discussed the role of an independent care partner.

Participants felt care partners could have a role where there is uncertainty in the guidelines, disagreement with the provider, and when there are short term issues to navigate or in times of crisis. It was agreed that a government body appointing someone would not be appropriate, nor would someone not in the same state or location.

Some participants identified that advocates are already in place and could also function as care partners. OPAN is well placed to provide such a role because it is independent of providers and has a structure in place.

The terminology of 'care partner' is problematic. It is acknowledged that older people prefer this to case manager or care manager, but there is potential for confusion with My Aged Care nominated representatives who act on an older person's behalf. Care partner is a term used by Dementia Australia advocates to refer to family carers/significant others and the Aged Care Quality and Safety Commission has a 'partner in care' program for people living in residential aged care. There must be clarity about the different roles of a care partner, an enduring guardian, or a power of attorney.

Information

To enhance choice and control, participants want and need more information on changing providers. For example, a 'yellow pages' or booklet which lists providers, what they offer and a ranking. It is difficult to know how to choose currently as the available information does not support making this choice. While there is some information on My Aged Care, this information is not always accurate and is difficult to navigate, especially for those who might be technologically challenged, or who don't have access to internet/technology.

Mr Nick Morgan, Assistant Secretary, Home Support and Assessment Branch, Department of Health and Aged Care posed two questions:

1. The challenge in the model put forward is an older person can select different providers to deliver different services. These providers would be paid an hourly rate after delivering the service. The government will set the price. There will be a quarterly budget to spend on different services. *However, what is the recommended approach if a recipient gets to the end of the quarter and does not have enough funds for the providers?* For example, one option is for a care

partner to ensure the individual is within their budget. Otherwise, individuals will need to do this themselves with tools offered for support. It will not be compulsory to have a care partner and individuals would be able to choose who is a care partner.

2. Providers would have set prices. Self-managing would not give a financial advantage in terms of changing providers. To what extent are participants choosing self-management for price reasons and would recipients self-manage under the proposed model?

In response to a question of clarification, it was confirmed there will be the ability for invoices to be paid as quickly and frequently as possible.

Feedback highlighted that there is still confusion around the term 'provider'. A service provider is someone who comes in the door. There are currently 'umbrella' home care providers looking after legal matters and people coming into the home to deliver services. There needs to be clarity about whether the provider would be an individual worker or a provider who charges to manage a package. It seems an additional complication for government to have individual workers registering as providers.

Participants also queried how a fixed price model for services would account for care providers who need degree level qualifications. One recipient advised of achieving continuity of care by paying above the award rate and choosing people who equate with their lifestyle.

Quarterly budgets

Some participants felt the system works well now, and the proposal will create administrative problems. It was acknowledged there are many people without the ability to self-manage under the proposed system. It was felt the government would need to have oversight and intervene to ensure people do not overspend. Some felt the proposal was inflexible, reflecting a lack of understanding of older people's lives. Many cannot plan three months in advance and their needs change regularly.

It was suggested that Services Australia/Medicare could be used to look after the payments. In terms of registration of service providers, most are already registered.

A question was asked on what will happen to current excess funds when older people transition to the new system. The Department advised that no existing home care

package recipients would be disadvantaged. The aim of quarterly budgets is flexibility within the three months. The current discussion paper says there is a budget. There will be set prices on hours so participants will know how many hours can be purchased. The 25% pool will be available for purchasing extra services.

As part of the consultation on self-management, discussions also focused on the proposed quarterly budgets. Some commented that quarterly budgets could be too complicated to manage and that a monthly budget is preferable with the ability to be able to track real time expenditure. Many flagged concerns for people with chronic and complex conditions who can become unwell for long periods and then may need significant additional services once they are well. There needs to be flexibility to enable accumulation of supports beyond the 3 months for people with fluctuating needs so that increased levels of supports can be provided once the person needs services again.

It is of concern that some people self-managing their supports, particularly if they are doing this largely through sole contractor arrangements, will also need to exceed their quarterly budgets from time to time. It is not clear whether they would also have access to a pool of funding to cover overspends to cope with additional needs within the quarter or whether they would need to go through a provider to access this.

There were eight key issues arising from the conversation and feedback:

1. How to ensure the assessment is right, timely and for the right amount of money.

2. How to ensure timeliness of payment to service providers.

3. How do we treat excess funds so people can save for larger items?

4. Concerns about registering individual providers and administrative costs, and if there is a need for registration.

5. Concern about quarterly budgets and if it gives enough flexibility as needs change.

6. Impact on the fees the individual is paying.

7. How people find the providers.

8. Pricing questions and queries about how it works.

In response to the question on what is delivered through self-management in addition to a cost saving, participants listed the following as benefits:

- receiving choice and flexibility

- having the feeling of empowerment and autonomy

- access to local support people.

Participants wanted to reflect on the implications and talk with OPAN regarding further opportunities to submit feedback or be involved in the consultation process. It was noted the area with the most unanswered questions was how self-management will operate in the new in-home care program.

Recommendations

Awareness and choice	
There is no clear definition of self-management, causing confusion for older people and providers.	• agree on a common definition, including the roles and responsibilities of different players (provider, worker, older person, family/carer, etc.) where a person is self-managing and communicate this to stakeholders.
Many people don't know that they can self-manage their care or how to start.	• promote self-management through program guidelines and My Aged Care • require providers and/or assessors to talk to older people about the option to self-manage • simple language videos, flyers/pamphlets to explain benefits and/or a how to guide for older people and their families • ensure all people have the choice to self-manage.
Scope	
Current guidelines are not clear regarding what's in and out of scope.	• revised guidelines developed in co-design with older people and providers • define co-design • use plain language not jargon.

Guidelines are bureaucratic, difficult to interpret and make sense of.	• revised guidelines developed in co-design with older people and provider.
Older people and providers can have differing interpretations of the guidelines and there is no external body to assess 'grey area' services or items, except the Aged Care Quality and Safety Commission.	• ability to contact an independent advocate/ mediator or care partner who understands the diverse needs and experiences of older people and the intent of the in-home support program to determine whether a service is within or out of scope.
Inconsistent application of when assessment by a health practitioner is required to determine the need for a service/item.	• guidance material for consumers and providers on provision of Assistive Technology (AT) such as produced by Independent Living Assessment Australia • such guidance to distinguish between low-risk AT that can be readily purchased, AT that consumers should seek written or professional advice on prior to purchase, and AT that needs to be prescribed by an allied health professional.
Responsiveness	
Lack of flexibility for people to adjust services in response to changing preferences, priorities and emergencies.	• people need to be able to access additional services, adjust services or cancel services as needed, particularly where urgent.

Control and judgement	
Some providers determine the services a person gets based on their own assessment and/or service offering rather than what the person says they need or want.	• well qualified and experienced assessors who respect older people's agency and work to ensure care plans reflect both individual needs and the aged care funding framework • providers respect assessments and reports provided by health care professionals who are familiar with their clients' needs.
Some providers or workers make judgements about how a person chooses to live their life or what services/items a person wants to access.	• define/clarify every stakeholder's role in relation to older people who self-manage.
Care managers	
Care managers are often not well trained or qualified.	• define the qualifications/experience required for care managers and who a care manager is.
Care managers work for the provider (so are not able to provide independent advice).	• ability to engage care managers who are independent of other providers delivering care and services (where wanted or needed).
Inflexible approach to engaging with care managers.	• provide flexibility for older people to engage with a care manager on an as needed (rather than on an ongoing) basis.

Fees and costs	
Management fees charged are often not reflective of the quality of the service delivered	• Aged Care Quality Standards applicable to package management and care management.
Significant variation in administration and care management fees between providers	• controls regarding service fees to be considered as part of the new in-home care program.
Payment delays by providers to contractors	• timely payment systems to ensure recipients are not out of pocket for purchase of goods and services.

Safeguards

Some of the hard questions arising from self-management are identified below, including some ideas put forward by older people to help stimulate discussion. It must be noted that these measures are proposed to act as safeguards only where required and for the minimum time needed; it is not proposed that such safeguards or protections would apply to all people who self-manage.

How do we make sure the more vulnerable among us who are self-managing don't fall through the gaps as we deteriorate?

Proposed measures included:

- assessment to check ability of person to self-manage

- care partners are readily available, if and when needed and chosen by the older person where possible

- regular monitoring and reassessment by the provider or an independent care partner

- access to appropriately trained and knowledgeable advocates focusing on consumer needs.

Who/what guides those of us who are self-managing regarding the appropriateness of expenditure when it's in the grey zone?

Proposed measures included:

- clear, detailed guidelines that can be understood and consistently interpreted by older people and providers
    - such decision guidance should prioritise the physical, emotional, social, cultural and spiritual wellbeing of the older person
- connections with GPs/allied health professionals for clinical needs
- access to appropriately trained, independent advocates
- keep the considerations simple and clear cut.

Do we need mechanisms to deal with the situation where those of us who are self-managing with multiple providers expend our budget and need additional services?

Proposed measures included:

- alerts for people who are spending their budget more quickly than expected
- online or app-based budget management tools
- oversight of expenditure in real-time
- temporary support from a care manager /care partner where needed
- budgeting support from financial advisors.

Representatives from the Department offered additional context:

- matters raised in the session will be written up and will incorporate matters raised through the survey so it is clear what people want
- what good self-management looks like differs for individuals
- policy is being developed and therefore the environment is changing.

The Department has a webinar and Q&A session on 7 December relaying what has been heard through consultations and initial responses to the key areas. Work will occur with key groups through until February 2023.

Additional issues were raised about service navigation and costs. It was acknowledged that there are good advocates available, and the model needs to be expanded so people who are lost within the system can get the support they need. The Care Finders

initiative will commence on 1 January 2023, and it could be expanded to include care partners. Clarification was also sought on costs for self-funded retirees in the new program. The Department advised it is still working with government on the approach to consumer contributions.

Summary

The consultation raised more questions than answers. Workshop participants appreciated that it was an open and frank forum that enabled people to contribute. People felt that additional forums would be useful to continue to explore how to make self-management a workable option.

It is clear older people want to be involved in co-design of self-management within the new in-home care program. It was noted there are different models and approaches preferred and described by participants. Flexibility on implementation is key as people have different hopes and understandings of services and supports.

The key themes of flexibility in service delivery and management of funding were emphasised throughout the workshop. Self-management is not undertaken for cost reasons, it also offers empowerment, choice and control. Directing relationships, quality of service providers, and effective comparison between service providers are also important themes. It was noted that underpinning issues around human rights and the Charter of Aged Care Rights need to be understood by all aged care providers.

Conclusion

OPAN does not believe that the level of choice and control sought by older people has been fully captured in the design of the new in-home aged care program. Older people have informed OPAN that despite numerous consultations with all stakeholders, a lot of confusion, misinterpretations, and misunderstandings still exist. This is creating serious anxiety amongst older people, which is impacting on their mental health and wellbeing.

OPAN recommends that the Department of Health and Aged Care work with older people to further explore and design this option. It has been suggested that this process could be supported with access to an independent and appropriately governed platform where people seeking in-home care can view and select support workers directly, manage their home care budget and share information when needs change. This would not negate the need for care plans and needs to allow access to flexible levels of care monitoring as needs change over time.