Self-managed Home Aged Care Support

Research Report

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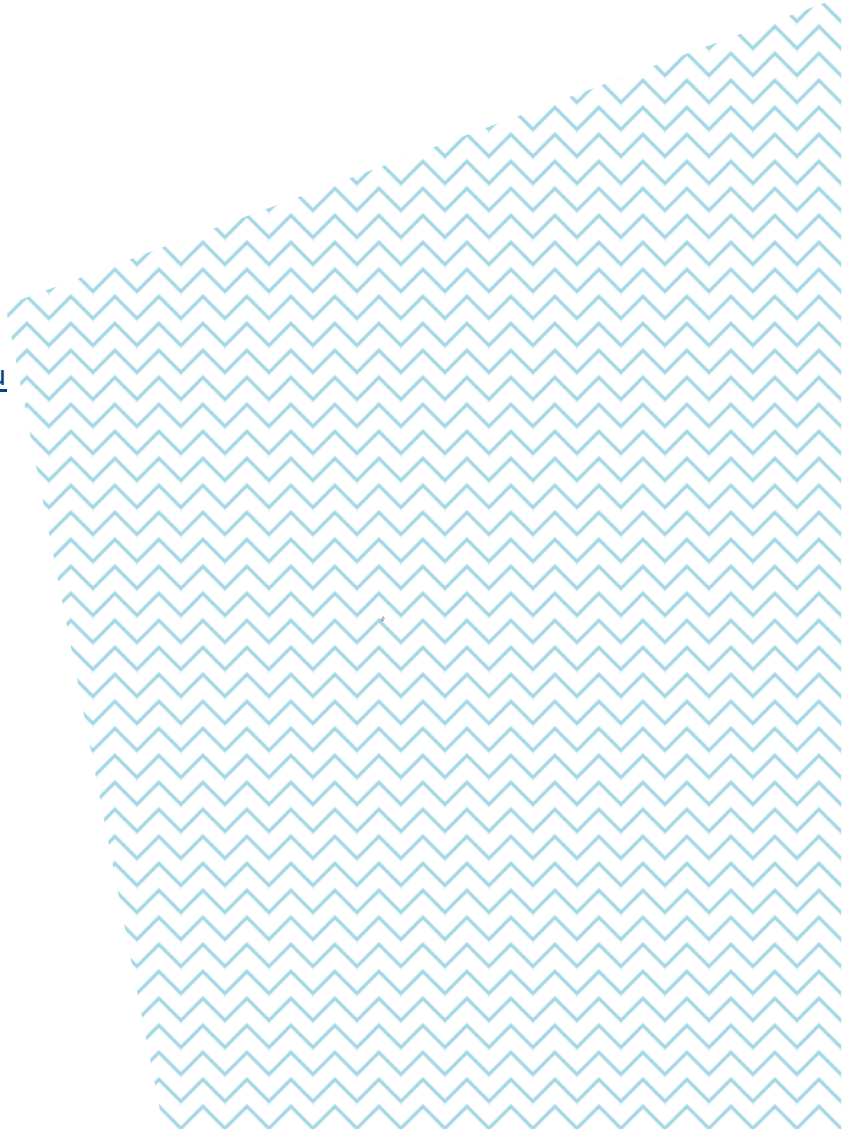Laragy, C. & McVilly, K. (2024). *Self-managed Home Aged Care Support Research Report*. The University of Melbourne, School of Social & Political Sciences, Melbourne, Australia.

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Summary

Empowered Ageing commissioned *The University of Melbourne* to study how self-managed aged Home Care Packages can be delivered effectively and safely. *Empowered Ageing* is an approved home aged care service provider that specialises in supporting people to self-manage their aged Home Care Packages. The *Royal Commission into Aged Care Quality and Safety* (2021)[1] identified risks associated with aged care. This study investigated the benefits and risks to:

      i)   older people who self-manage their aged Home Care Package,
      ii)   their support workers, and
      iii)   ways to mitigate these risks.

The University of Melbourne Human Research Ethics Committee reviewed and approved the study design. Thirty semi-structured interviews were conducted online using Zoom with consumers who self-managed an aged Home Care Package (n=5), a NDIS package (n=1); family representatives who managed an aged Home Care Package (n=3), a NDIS package (n=2); contracted support workers in aged care (n=2), in NDIS (n=2), in both aged care and NDIS (n=3); contracted enrolled nurse in aged care (n=1); aged care service providers supporting self-management (n=3); aged care planner / coordinator (n=2); aged care consultant (n=2); NDIS staff trainer (n=1); manager online employment platform (n=1); technology company CEO (n=1); and policy academic (n=1).

The findings highlighted how older people can successfully self-manage their aged Home Care Package and how risks can be managed. While self-management is not wanted by everyone, those who chose to self-manage reported benefits. These included having more choice and control over their support, especially being able to select support workers. Interviewees felt much safer selecting support workers who matched their needs and interests compared to having unknown rostered agency staff come to their home. Contracted support workers often worked for one consumer for years. Modern technology was an asset that facilitated self-management. Technology assisted with recruiting support workers, scheduling work, managing accounts and payments, and enabling providers to monitor spending and be alerted to any unusual payments or fraud.

Self-management occurred within a complex service system where there was inadequate funding for community services and Home Care Packages as well as workforce shortages.

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[1] *Royal Commission into Aged Care Quality and Safety* (2021) https://www.royalcommission.gov.au/aged-care

These challenges impacted on older people in the study who self-managed and their family representatives. While workforce shortages were a major concern across the sector, most interviewees used informal networks and online recruitment services to find satisfactory workers. However, recruitment was a challenge for some interviewees from time to time.

Self-management required consumers and their family representatives to navigate complex family dynamics and manage support workers and other services. Some consumers had the confidence and skills to competently manage these situations after a lifetime of relevant experiences. Others were beginning to develop skills and sometimes felt challenged. Everyone needed access to information and advice from time to time, particularly those developing new skills.

Interviewees discussed the need to balance consumer's protection and care with their right to 'dignity of risk', to build their capacity, and to choose their lifestyle. Multiple risks were identified with all aged care services, including self-management. Older people can be vulnerable to perpetrators of abuse from within and outside their families. Their rights can also be overridden subtly by others with well-meaning intent. These include service providers who want to minimise risks, surveillance and tracking technologies that are not transparent, and by families wanting to protect. Strategies to mitigate risks need to be individually tailored, with diverse and individual safeguarding strategies developed. Restrictive strategies should only be imposed when proven necessary and expressly stated with necessary consents provided, if necessary, through appropriate Guardianship mechanisms.

Interviewees referred to instances of abuse reported in the media and linked these to consumers becoming isolated and neglected. They thought that risks of harm can be minimised, and safeguards maximised by the older person having a wide circle of personal and social connections. Numerous strategies for strengthening personal and social connections were suggested. It was considered essential to tailor safeguarding strategies to the older person's needs and wishes. Safeguarding strategies included using aged Home Care Packages to support consumers to participate in their chosen social activity such as a book club or community group and asking each older person to nominate several people to become involved in their planning meetings or form a 'circle of support'. Formal 'circles of support' consisting of unpaid family and friends were thought to provide excellent safeguards. In instances of family abuse, they provide a critical safeguard by including community members.

To maximise their safety, consumers needed relevant information and support to build their decision making capacity to make informed decisions. They needed to know that self-management is an option, and it comes with rights and responsibilities. They needed to understand the purpose of aged care support, how to use their personal resources and assets along with government support to remain living at home, statutory regulations, and home care provider responsibilities.

Providing current and easy to understand information is challenging. Although there are multiple sources of information available, older people often did not access them. Facebook peer support groups were useful for some older people but not for everyone. Interviewees asserted that assessors, coordinators, and care managers needed to be well informed and highly skilled at assessing needs and passing on relevant information.

Self-management had both benefits and challenges for aged care consumers and their support workers. Support workers liked being able to choose who they worked for and being able to negotiate pay rates and work times. Pay was often higher than agency rates and they could roster work around family and carer responsibilities. Many support workers were recruited through personal networks or through online platforms. Self-management expanded the pool of support workers because many would not have registered with a traditional service provider and work to a roster with unknown consumers. One support worker was an award winning author who supplemented her income supporting selected consumers.

However, support workers also faced challenges. Sometimes they felt unsafe in peoples' homes without a provider supporting them. Some felt obligated to work unpaid hours when the older person's package was insufficient to meet their needs, and some did not have the hours of paid work they wanted. Some younger, inexperienced support workers, especially from non-English speaking backgrounds found it difficult to assert their rights with consumers. The more experienced support workers had more confidence and were prepared to walk away from any unsafe situation. Despite these challenges, most support workers found contract work for selected consumers was more rewarding as it gave them more choice and control than rostered agency work with unknown consumers. Having access to training, information, and support from a provider was widely valued but not always available.

Service providers and other professional staff interviewed spoke of the challenges they faced resulting from the changing regulatory environment. At times the *Department of Health and Ageing* and the *Aged Care Quality and Safety Commission* gave opposing directives.

Overall, the findings endorse self-management as a viable option for older people and for support workers. There are risks with self-management, as there are with all home care arrangements. The findings show that these risks can be managed. Skilled case managers and coordinators, and a strong informal 'circle of support' are effective. A draft of the new aged care legislation was released for review in December 2023. An initial assessment shows that the draft focuses on compliance and is not supportive of self-management. It remains to be seen if the many community groups opposing the draft legislation can change its content.

Background to the study

Empowered Ageing commissioned *The University of Melbourne* to undertake an independent study of self-managed home support services and how they can be delivered effectively and safely. *Empowered Ageing* is an approved aged care service provider specialising in supporting people to self-manage their aged Home Care Package. People who self-manage take an active role in organising supports and services and recruit their support workers in partnership with an approved aged care provider. The provider is responsible for the quality of services provided. Thirty interviews were conducted with people from across Australia who were: older people who self-managed their Home Care Packages, family representatives who managed for the older person, support workers, aged care providers, an aged care coordinator, an aged care consultant, a NDIS staff trainer, a manager at an online platform connecting support workers and consumers, a technology company CEO, and a policy academic. Older people who self-manage and their family representatives will be referred to as consumers.

The study was conducted following the *Royal Commission into Aged Care Quality and Safety* (2021) and the *Productivity Commission's* (2022) findings that self-management in aged home care and in the *National Disability Insurance Scheme* (NDIS) brings both benefits and risks to people who self-manage and to their support workers. Interviews were conducted between September 2023 and April 2024 when the sectors were in a state of flux. The *Exposure Draft Aged Care Bill* 2023 was released on 14 December and the new federal *Fair Work Legislation Amendment (Closing Loopholes)* Act 2023 was introduced to Parliament on 4 September and received Royal Assent on 14 December. Most interviewees had not seen these documents before being interviewed.

Selected reports relevant to self-management of aged Home Care Packages are summarised below. These provide a framework for analysing the comments about self-management recorded in the study. Different terms were used across the literature to describe various forms of self-management. These included individual funding, self-directed support and individualised support.

Literature review

There is an extensive range of documents relevant to self-managing aged Home Care Packages. This includes the United Nations charters on human rights, national policy frameworks, legislation, service standards, guidelines, principles such as choice, control, self-determination, dignity, and respect (Braithwaite, 2023)[2]. Selected documents are reviewed below that highlight key concepts and controversies concerning self-managed aged Home Care Packages. These topics guided questions and discussion in the interviews conducted.

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[2]   Braithwaite, V. (2023), *Social care and support experience – influencing factors*, School of Regulation & Global Governance, Australian National University (Unpublished).

Productivity Commission, Aged care employment, Study Report. (2022)[3]

The *Productivity Commission* examined the aged care workforce following the concerns expressed by the *Royal Commission into Aged Care Quality and Safety* (2021). They considered self-management in considerable depth, reviewed submissions to the Royal Commission, and conducted further consultations. They concluded that self-management generally advantages workers and consumers. They disagreed with criticisms that self-management necessarily exploits and disadvantages workers. They found that self-management and flexible working arrangements: encourages new entrants into the care workforce; facilitates more workers becoming available in regional and remote settings where there are no viable home care providers; aids the retention of workers who would otherwise leave the sector; allows consumers to pay lower fees to their provider and purchase more support; permits consumers to find support workers on online platforms, including those with diverse needs; and fosters continuity of care compared to ever changing agency rostered workers. The *Productivity Commission* concluded, "self-management ... has allowed consumers to have greater choice and control over the services and people they wish to enter their homes, leading to improvements to a number of care outcomes" (p.54).

Per Capita, Contracting care: the rise and risks of digital contractor work in the NDIS. (2022)[4].

The union supported think tank, *Per Capita*, produced a paper on the risks faced by contracted workers in the NDIS. These risks apply equally to aged care workers contracted under self-managed arrangements. This paper was highly critical of all contracted work. It argued that workers were disadvantaged. It supported the union's position for all jobs to be full time and ongoing. This is a theoretical paper not based on practice research. It hypothesised that the hazards for contractors would be lower income security, more complex administrative requirements, fewer training and peer-to-peer support opportunities, higher personal liability risks, and fewer social protections like sick pay, parental leave, and superannuation contributions. The paper raised concerns that contracted workers will undercut the price of registered employment-based providers and threaten their viability. A further concern was that consumers who contract workers might be regarded as employers in future legal judgements and have additional legal and financial obligations. A significant point of difference to the Productivity Commission's (2022) study was Per Capita's argument that contracted workers will focus on discrete tasks and not develop a trusting and continuous relationship with their consumer. The *Productivity Commission* (2022) found the opposite.

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[3]   Productivity Commission. (2022). *Aged care employment, Study Report*. Retrieved from
https://www.pc.gov.au/inquiries/completed/aged-care-employmdent/report

[4]   Per Capita. (2022). *Contracting care: the rise and risks of digital contractor work in the NDIS*. Retrieved from https://apo.org.au/node/318417

Laragy, C., & Vasiliadis, S. D. Self-managed aged home care in Australia – Insights from older people, family carers and service providers (2022)[5] .

COTA Australia conducted a trial of self-managed home aged care with 103 consumers during 2018-19 that was evaluated by Laragy and Vasiliadis. The self-management model was codesigned by COTA Australia, consumers, and seven providers involved. The primary aim of the evaluation was to examine whether self-management improved consumers' perceptions of their choice, control, and wellbeing. Qualitative interviews and quantitative surveys were used to evaluate the outcomes of self-management.

The overall findings of the self-managed model were positive. Participants reported improved wellbeing and a preference for self-managed over agency managed supports because they had greater autonomy and control over spending, they had more consistent staffing by choosing their support staff, and they paid lower administration fees. There was no evidence of increased risks or fraud. However, the statistical analysis of survey ratings before and after the trial showed no statistically significant differences. Despite the statistical findings being ambiguous, participants expressed strong support for self-management in interviews. The study found that successful self-management requires consumers and their family carers to have information, clear guidelines, and supportive providers.

The study concluded that transitioning from agency managed services to consumer controlled, self-managed services required profound organisational change. Case managers were familiar with managing services for older people. They had to relinquish some control and learn new roles as facilitators and supporters, and service providers needed new financial and data management systems to manage individual accounts.

Royal Commission into Aged Care Quality and Safety (2021)[6]

The *Royal Commission into Aged Care Quality and Safety* was established in 2018 and received over 10,000 submissions during the following two years. These included heartbreaking stories of abuse, neglect, and failures of regulation and governance of aged care services. Some submissions argued that vulnerable older people would be better protected by having more professional involvement, clinical supervision, case management oversight, and tighter restrictions and regulations. While acknowledging the need for competent professionals and effective processes, alternative arguments suggested that

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[5]   Laragy, C., & Vasiliadis, S. D. (2022). Self-managed aged home care in Australia –Insights from older people, family carers and service providers. *Health & Social Care in the Community, 30*(5), e2518-e2529. doi:10.1111/hsc.13695

[6]   Royal Commission into Aged Care Quality and Safety. (2021). *Final Report: Care Dignity and Respect Vol.1*. Retrieved from https://agedcare.royalcommission.gov.au/publications/final-report

safety is promoted, and risks are reduced if supports are flexible, and older people can maintain their social and community networks with multiple people involved in their lives. These differing views giving priority to professional oversight verses community connections are mirrored in many reports and were discussed in the interviews.

The aged care workforce was another contentions topic discussed at the Royal Commission. Everyone agreed that worker shortages were exacerbated by low pay and poor working conditions. Union representatives lobbied for full time, permanent positions that would give workers job security. A contrary view was offered by some support workers, consumers, and service providers who wanted to prioritise flexibility in work arrangements. They argued that flexibility was in everyone's interests and workers could schedule their work around other commitments and lifestyle choices.

The two Commissioners, Mr Tony Pagone QC and Ms Lynelle Briggs AO, came to different conclusions about the causes and solutions to problems in the aged care sector. Tony Pagone QC tended to be critical of government agencies and favourably inclined to self-management, while Lynelle Briggs veered towards professional oversight and regulation. The Commissioners released a joint general statement about the purpose of the aged care system and the need for new legislation. They said:

> The purpose of the aged care system must be to ensure that older people have an entitlement to high quality aged care and support and that they must receive it. Such care and support must be safe and timely and must assist older people to live an active, self-determined and meaningful life in a safe and caring environment that allows for dignified living in old age (Vol. 3, p.14).

The Commissioners made 148 recommendations for aged care sector reform without providing a clear roadmap for implementation. Work is continuing with the new aged care legislation and workforce industrial laws to find a way forward.

Fair Work Legislation Amendment (Closing Loopholes) Act 2023 was introduced to Parliament on 4 September 2023 and received Royal Assent on 14 December 2023.

The *Fair Work Legislation Amendment (Closing Loopholes) Act* 2023 contains measures that were still before Parliament at the time of writing[7]. A detailed analysis of this Act is beyond the scope of this review. However, it is noted that proposed changes to the Act are likely to impact on self-managed employment arrangements. While the intention of the Act is to strengthen worker's rights and workplace conditions, there are questions as to whether it might result in unintended negative consequences for support workers and aged care consumers. Of particular importance is the proposal to redefine the meaning of 'employee' and 'contractor'.

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[7]   Department of Employment and Workplace Relations, *Stand up for casual workers* https://www.dewr.gov.au/closing-loopholes/resources/stand-casual-workers

It is proposed that contracted workers will have the option to be reclassified as 'permanent employees' when they have worked for an employer regularly for over six months (12 months in a small business). If support workers are reclassified as 'employees', they will no longer be entitled to the casual loading that increases pay rates and instead will receive paid leave and theoretically have a permanent job. Aged care consumers employing support workers as 'employees' would have new obligations that include paying superannuation. The new laws are designed to stop organisations exploiting their casualised workforce. However, older people with Home Care Packages who contract regular support may not be able to guarantee ongoing work.

Strengthened Aged Care Quality Standards, Final draft, November 2023.

The final draft of the *Strengthened Aged Care Quality Standards* was released in November 2023[8]. These standards are important because they will guide the implementation of the new Aged Care Act when it is finalised. Providers will be held accountable to these Standards. The Standards have a comprehensive framework. Standard 1 relates to 'The Person' and describes i) person-centred care, ii) dignity, respect, and privacy, iii) choice, independence, and quality of life, and iv) transparency and agreements. Standards 2 to 7 relate to Organisations, Care and Services, the Environment, Clinical Care, Food and Nutrition, and the Residential Community. While acknowledging the importance of the Standards, their recent release has not allowed time for them to be evaluated in this report.

Exposure Draft Aged Care Bill 2023. A Bill for an Act about aged care, and for related purposes (Health and Aged Care), 14 December 2023[9]

An exposure draft of the much anticipated new aged care legislation was released on 14 December 2023. The draft was developed following extensive consultations. A preliminary review of this complex 347 page Bill reveals an emphasis on the rights of individuals accessing funded aged care services. The *Objects of this Act* (S.5) have statements consistent with the principles of self-management. They say the Act will:

- uphold the rights of individuals,
- assist individuals accessing funded aged care services to live active, self-determined and meaningful lives,
- support individuals accessing funded aged care services to effectively participate in society on an equal basis with others, thereby promoting positive community attitudes to ageing,
- enable individuals accessing funded aged care services to exercise choice and control in the planning and delivery of those services.

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[8]   Department of Health and Aged Care. (2023). *Strengthened Aged Care Quality Standards, Final draft, November 2023*. https://www.health.gov.au/sites/default/files/2023-12/the-strengthened-aged-care-quality-standards-final-draft-november-2023.pdf

[9]   EXPOSURE DRAFT Aged Care Bill 2023. A Bill for an Act about aged care, and for related purposes (Health and Aged Care), 14 December 2023. https://www.health.gov.au/resources/publications/exposure-draft-aged-care-bill-2023

Stephen Duckett's (2024)[10] critique of the Draft Act argued that despite mention of individual's rights, the Draft Act gives people few rights. Individuals have a right to an assessment and to palliative care, but no right to services in between. Government has no obligation to provide necessary services between the initial assessment and palliative care. Government has "effectively washed its hands of any obligation to ensure that people can get the services they need, presumably on the invalid assumption that services will just emerge to respond to demand expressed in a perfectly functioning market. The idea of a government role in service development is missing from the Act" (p.1). Duckett further argued that the:

> "new Act smacks of 'rights washing'", with high sounding rhetoric included to placate consumers and advocates, allowing providers to continue on their way unimpeded, and government to eschew any role in creating and steering a consumer-focused service system. Section 21 of the Draft Act provides government and industry with a 'get out of jail free' card when it says: 'Nothing in this (aged care rights division of the new Act) creates rights or duties that are enforceable by proceedings in a court or tribunal'"(p.1).

As Duckett pointed out, the Draft Act relies on market forces to develop services with government holding providers responsible for service delivery. It seems likely that the new Act will create a risk averse environment where providers can deny older people their right to take considered risks. It may increase obstacles to older people self-managing.

The Older Person's Advocacy Network (OPAN) [11], during a webinar in August 2023, discussed the competing principles of the provider's duty of care to protect older people and people's rights to take considered risks. Concerns were raised about providers and regulators being overly protective of their own reputations and denying the rights of older people. It seems possible that the new Act will diminish rather than enhance older peoples' rights.

Research method

The aim of this study was to explore contested views about self-management of aged Home Care Packages with key stakeholders. The specific objectives were to identify:

i) Any benefits that self-managing an aged Home Care Package gives to the consumer, their family carers, or their support workers,

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[10]　　Duckett, S. (2024). Proposed new Aged Care Act leaves gaps in rights. *Pearls and Irritations John Menadue's Public Policy Journal, January 12*.

[11]　　Older Person's Advocacy Network, Webinar 29/08/2023). *Exploring the proposed new Aged Care Act* https://media.accessiblecms.com.au/uploads/opan/2023/08/OPAN-Transcript_290823.pdf

ii)   Any risks that self-managing an aged Home Care Package brings to the consumer, their family carers, or their support workers,

iii)   Strategies to minimise any risks identified,

iv)   Ways to deliver self-managed support services safely and effectively.

The intent of this study was to use the findings to optimise the delivery of self-managing support services and minimise risks in home aged care. It is intended that the findings will lead to improved services and improved quality of life for older people.

The study had 30 semi-structured interviews conducted online using Zoom. They were of approximately 60 minutes duration. Appendix D shows the interview guides. The categories of interviewees are shown in Table 1 below. Semi-structured interview questions allowed topics to be explored in depth. An action research framework[12] allowed ideas raised in earlier interviews to be explored in later interviews. Conversations were recorded and transcribed. The automatic Zoom transcription was used for 27 interviews. Three interviews were professionally transcribed because the automated service did not accurately record their accent or their complex ideas.

The transcribed interview records were uploaded into the qualitative analysis software NVivo. A combination of inductive and deductive methods was used. Themes identified in previous reports and papers were considered and new themes added when introduced by interviewees. Because of the small sample size only descriptive analysis was used.

The University of Melbourne Human Research Ethics Committee reviewed the proposed methodology and approved the study, see Appendix A. Plain Language Statements were given to all interviewees prior to interviews, see Appendix B. Interviewees gave their written informed consent to participate, see Appendix C.

Recruitment

This sample was targeted and does not represent the wider population of older people who self-managed their home aged care support. The study recruited older people and their family representatives who were successfully self-managing their aged Home Care Package. A demographically diverse sample was sought with participants from different ethnic backgrounds coming from urban, rural, and remote areas. While there were urban and rural consumers and one First Nations consumer, the sample is not representative of Australia's diversity. Interviewees were initially identified through Dr Laragy's professional networks and later using snowballing techniques. Interviewees who self-managed were asked to inform their support workers about the study and invite them to contact Dr Laragy if they

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[12]   Wadsworth, Y. (1991). *Everyday Evaluation On The Run*. Melbourne: Action Research Issues Association.

wanted to be interviewed. Four support workers were recruited this way and the remaining three came via other interviewees. This method ensured that all support workers had experience of self-management. All consumers and their support workers were informed that no personal information about each other would be sought. The interviews would focus on the advantages, challenges, and risks of self-managed arrangements. The inclusion of NDIS participants who self-managed and their workers provided an opportunity to compare the two fields. All interviewees were initially contacted by email. This was the usual method of communication with consumers who self-managed and their workers.

People who self-managed, their informal family carers, and support workers were given a $50 Zenith digital prepaid Visa card in appreciation of their time.

Limitations of the study

The study had a small, targeted sample of people who self-managed and their support workers, plus service providers and other professionals who supported self-management. Insights were offered into self-management from people with in-depth knowledge and experience. However, as the sample was not randomised, the findings cannot be generalised to the wider population. The study does provide important guidance on how to maximise the benefits and minimise the risks of self-management.

Participants

Table 1 below presents a profile of the participants interviewed.

Table 1:   Interviewee characteristics (n=30)

Older people who self-managed their aged care package (5), NDIS package (1) Female 6.   One older person was First Nations. Location: ACT (2), Melbourne VIC, Rural NSW, Sydney NSW, SA
Family representatives who managed for older people (3), for NDIS participants (2) Female 4, male 1. One woman also worked as coordinator for an aged care provider supporting consumers to self-manage. Location: ACT, Perth WA, Rural WA, QLD, VIC
Contracted support workers in aged care (2), in NDIS (2), in both aged care and NDIS (3) Female 7. One woman also worked as coordinator for aged care provider supporting consumers to self-manage. Location: ACT, Melbourne VIC (3), Perth WA (2), Sydney NSW
Contracted enrolled nurse in aged care (1) Female 1. Location: Sydney NSW
Aged care service providers supporting self-management (3) Location: National, NSW, WA

Aged care planner / coordinator (2); aged care consultant (2); NDIS staff trainer (1); manager online platform connecting support workers and consumers (1); technology company CEO (1); policy academic (1) Female 7, male 1. Location: ACT (2), Melbourne VIC (2), Brisbane QLD, Rural QLD, Sydney NSW (2)

*Note, six professional interviewees also managed a package for a family member. They provided insights from multiple perspectives.

Findings

The benefits and the challenges of self-management reported by consumers, support workers, and professionals in the industry are presented below. Older people and their representatives were successfully self-managing their aged Home Care Package and emphasised the benefits. They argued that the risks can be managed. Interviewees stressed that there are inherent risks in all home aged care support whether self-managed or agency managed. This is mainly due to life circumstances often being complex, and people becoming frailer and more dependent with age. Support, regular reviews, and strong social networks were recommended as the best ways to mitigate risks.

Consumer benefits

Consumers who self-managed and their family representatives spoke of many advantages they gained by self-managing their aged Home Care Package compared to receiving agency managed supports. Although they had to do more work to negotiate services and support and manage their accounts, everyone interviewed considered that the benefits outweighed the effort. Each person had a unique story to tell, and it is not possible to include everyone's story in detail. One consumer's story was chosen because many features resonated with others.

Rosemary's story

A 77 year old woman spoke of the advantages she gained from self-managing her Home Care Package. I will refer to her as Rosemary. Rosemary lived alone in a large house in a capital city. She was warmly and closely supported by her son and his partner, and she had a wide social network. She was a social activist involved with human rights and peace initiatives and did voluntary work with refugee communities.

Around 2018, Rosemary had serious medical problems following a major car accident. These included a stroke and brain surgery. At one point she was in hospital and the social worker told her that she could no longer manage at home, and she needed to move to a nursing home. Rosemary discovered later that the social worker knew nothing about self-management. A close friend of Rosemary, who held her Power of Attorney in partnership

with her son, was also a social worker. She knew about self-management in the aged care system. She managed her own mother's aged Home Care Package.

With advice and support from her son and her friend, Rosemary returned to live at home. She chose a service provider that supported self-management, received oversight and advice from her case manager, and used her package to buy Lite n' Easy meals, domestic help, and allied health assistance. She contracted one of the Afghan refugees she had previously assisted as her support worker. He worked six hours per week providing light domestic help and driving her to appointments. She could manage her own personal care. By choosing to self-manage, Rosemary paid lower service provider fees and had more funds to purchase supports. Rosemary's son and her friend were in regular contact with her and her support worker, and they kept a close eye on how things were going.

Moving ahead five years to when Rosemary was interviewed, she described her joy and satisfaction with her living arrangements. Rosemary's son and her friend continued to provide close support and oversight, and the same support worker continued to provide six hours of help per week. By this time, he was a qualified brick layer and did general maintenance around the house in addition to other duties. She felt they both benefited from their congenial working relationship. He told her his English had greatly benefitted and Rosemary enjoyed his company and felt safe and cared for. She said his presence was reassuring for her family,

> "My family are so grateful to him because they don't have to worry about me."

Rosemary had resumed her social activist work and was responsible for running an internationally recognised 'Peace Education Program' in prisons and schools, with a new school program to commence the week following the interview.

She was grateful that she had a rich and fulfilling life and was not living in a nursing home. She considered that her support worker was important in enabling her to live so well. She said,

> "I'm enjoying my life more than ever… We look after each other, .. he (support worker) is my main source of support….it's a caring relationship"

Rosemary needed considerable advice from her friend and her case manager when first self-managing her aged Home Care Package. She always paid her accounts immediately and was reimbursed by her provider. Initially she sent invoices from her chiropractor, podiatrist, cleaner, and gardener to her provider as they arrived. Over time she became more confident, and she learnt to submit receipts monthly. She gained considerable satisfaction from her ability to self-manage. She said,

> "I've always been good at managing finances… It's so empowering and makes me more responsible for my own wellbeing."

While self-management brought many benefits, it could not overcome staff shortages. Rosemary continued to look for an occupational therapist without success. She was aware there might come a time when she does not have the mental capacity to manage her affairs. She was confident that this would be detected by her son, her friend, and her case manager, and she would be well supported.

Rosemary contrasted self-management favourably with support previously received from a traditional service provider. She said,

> *"There was a different person coming in every week, and then sometimes they didn't turn up. Every time there was someone new and it was exhausting trying to show them where everything was... It was more of a hassle than a help to me."*

To Rosemary's further annoyance, the case manager repeatedly told her that she needed more social connections. Rosemary said,

> "*They kept telling me what I wanted, and it wasn't what I wanted. They said, 'you need to have more social connections'. But I've got social connections with people that I choose to be with*."

Rosemary was relieved and grateful that her aged Home Care Package enabled her to live the life she wanted. She said,

> *"I'm enjoying my life more than ever."*

Choice and control

Rosemary, like other consumers and their family representatives, chose self-management because it gave them greater choice and control over services than previously experienced with agency managed support. They could purchase support from mainstream providers at lower costs, use different providers for different tasks, and tailor support and services to maximise their quality of life. A major factor in deciding to self-manage was dissatisfaction with agency managed supports. Interviewees disliked having to repeatedly induct new staff, having a limited range of support options, and paying higher management fees. Although they had to manage invoices, which was a burden for some, consumers preferred to self-manage. They found it easier to liaise directly with workers than organising times and tasks through a service provider.

An elderly consumer with multiple physical impairments had received physiotherapy treatment from one practitioner for some years. His private health insurance paid approximately half the cost of each consultation and he wanted to use his aged Home Care Package to pay the balance. However, his traditional provider insisted on paying the full amount from the package, which made no sense to the consumer. He challenged this decision, went to arbitration, and won. During this process he learnt about self-management. He transferred to a new provider that supported self-management and offered more choice and control. His wife said:

With traditional providers, "You don't know who's coming into your house. You don't know their skill sets. You are relying entirely on your service provider…Self-management is choice…Since we moved to self-management there has been no confrontation… I will choose self-management every day". (Consumer's wife)

"I would be loath to see self-management go... I don't want to see people completely lose that capacity to be masters of their own destiny in their old age." (Aged care support coordinator)

"I think the main thing is having control. And they [support workers] always turned up when they were meant to, unlike with the provider when sometimes the person didn't come or changed the date because they had other priorities". (Consumer's wife)

Choice of workers

Being able to select support workers and directly negotiate duties and times were deciding factors for many consumers who chose to self-manage. Most had experience of traditional providers sending a changing stream of workers. They wanted choice and continuity. Finding support workers who they were comfortable with was critically important because their lives were exposed to these workers – physically, financially, and lifestyle. They wanted to feel safe and secure. Having continuity of workers was particularly important for people with dementia and other neurological conditions who did not cope well with change. They found it easier communicating directly with one worker rather than negotiating through a provider. They could more easily adjust schedules for their convenience and that of the worker.

"I definitely want to self-manage because I want to be able to select my support workers. That was a big, conscious decision." (NDIS participant)

"People have the right to choose who sees them naked." (Aged care consultant)

"It might take them two or three goes [finding …] support workers. But then, when they find somebody, they build a really meaningful connection and have that ongoing relationship." (Service provider)

"She had the experience previously working with the CHSP (Commonwealth Home Support Programme). She had no control at all over who turned up at the door, .. or what time they turned up. It was very confronting for her. We had a worker who literally embezzled money and goods from her, and I put a complaint in to [the provider]. They sent someone else for three weeks and then they sent the same person. It was awful." (Consumer's daughter)

I self-manage my daughter's NDIS funding because, "w*e have more control, we can choose our staff, and we can save money too… Agencies send anyone to you… agencies charge you half of [my daughter's] funding. Self-management can save*

money. [My daughter] needs two workers and I can employ a second worker. With agencies I can only have one worker". (NDIS participant's mother)

Cost savings

Woven into most consumers' stories were statements about self-management saving on provider fees and leaving more funds to purchase goods and services.

One woman caring for her elderly husband with advance dementia had to wait nine months for funds to be allocated after his assessment. Waits of this duration and longer were common. During that time, the woman researched her support options and when funds became available, she moved directly to self-management. She wanted to choose workers, oversee the budget, and save on administration fees. Being computer literate, she confidently managed the administration.

> "*The flexibility and autonomy were excellent.*" (Consumer's wife)

Most consumers interviewed commenced with a traditional aged care provider when assigned an aged Home Care Package. The trajectory many followed was to become more knowledgeable and independent and move to a self-managed provider, recruit staff through Mable or another online platform, then move off Mable and recruit support workers independently to save money.

> "*Over time she's had three different providers… [Two traditional providers and then we found] a provider who allowed for self-management and that's what we did for the last few years. We found three support workers initially through Mable... but they eventually left Mable and set up their own ABN. We negotiated rates with them privately. On average it worked out to about $50 an hour, which the workers got rather than only half of it. It was an exceptionally good relationship, and the three of them formed a beautiful team.*" (Consumer's partner)

Many consumers said the self-management resulted in them paying lower administration fees. However, one consultant pointed out that paying self-managed provider fees and paying to recruit workers through an online platform such as Mable can be more expensive than paying a traditional service provider. Attention is needed to compare costs and services.

Technology & administration

Self-management relies heavily on technology for communication and administrative processing of invoices and budgets. After an initial orientation period, everyone interviewed was comfortable with the online systems their provider used. The systems varied widely across the three providers, with different levels of technological skills required. The three providers had systems to process invoices online, while one also allowed consumers to post in invoices. Overall, technology was seen as creating efficiencies, giving real time access to

budget balances, enabling family members to support consumers from afar, and it has the potential to combat fraud because transactions are transparent.

The tech savvy mother of a NDIS participant said,

> *"[Because I self-manage], I decide on providers [support workers], I negotiate, and I get the service agreement. Providers invoice me, I claim from the NDIS and then I pay the bills. The NDIS usually pays overnight. It's gotten quicker over time… You log into the NDIS portal where it's got all of your budget, you know what your funding is and your budget in the different categories….I use the same providers all the time so I don't have to keep entering the same details… I put in the date of service and the dollars. Click and it's done… I used to upload the invoices, but it was clunky and time consuming. I don't like uploading invoices. Now I keep all invoices separately so that I've got records [if I'm audited]. They've got that running incredibly well… I find it easy."* (NDIS participant's mother)

Technology also enabled several interviewees to support a family member to self-manage who lived interstate.

> "*Families can be quite involved, but not have to live next door anymore*." (Service provider)

To some extent, technology is being used to monitor spending and counter fraud and this is expected to increase in future.

> *"The technology innovation will create more efficiencies, safeguards, and fraud mitigation that once upon a time a human being would be largely responsible for. It will be very administrative".* (NDIS staff trainer)

Consumer challenges

While self-management resulted in many benefits, it also had challenges. It addressed some systemic problems such as inadequate funding because most self-managed providers charged lower management fees which resulted in more support hours. Self-management also addressed workforce shortages to some extent because there was a wider pool of potential workers in the community that was tapped into. However, each person faced a unique set of challenges that had to be managed. Challenges included the following.

Inadequate funds

A major concern among consumers and support workers was inadequate aged Home Care Package funding. This, combined with limited block funded community services restricted the wellbeing of older people.

> "We still need to block fund community programs… We are not funding packages to the point of being able to maintain community engagement. There has to be a

concurrent block funding model where you get State and Federal governments working together". (Manager, online platform connecting support workers and consumers)

Recruiting workers

Recruiting and training suitable support workers was a problem for some consumers and not for others. One consumer said,

"The most difficult thing at the moment for me is getting the right staff and training them to be person centred… [but this is easier than working with agencies] they didn't help me at all. I don't have that mental stress I had when I was dealing with agencies." (NDIS participant's mother)

Another consumer had trouble recruiting a reliable cleaner. After 'letting go' a few unsatisfactory cleaners who had advertised independently online, the consumer engaged a cleaning company. While the first agency cleaner was also unsatisfactory, the company responded to a request for another cleaner and sent someone who was excellent. This worker continued to provide services for some time.

Managing staff

Managing support workers required considerable skill. Some consumers had well developed management skills from previous work settings, and others drew on life skills developed raising families or being on community committees. The confidence level of consumers varied greatly. Even those who were highly confident had a steep learning curve when they commenced to self-manage. Having access to information and advice was essential as they learnt the processes, rules, and regulations.

Dilemmas within families

Family dynamics were often complex. Interviewees discussed the line between necessary protection and over protection of an older family member was not easy to define, especially when the person had dementia. One respondent and his sister managed their mother's Home Care Package and contracted support workers. A dilemma arose when their mother, who had dementia, directed her support workers to buy her alcohol. As the older person was unable to monitor her intake, she drank excessively and became intoxicated. While aware that they were overriding their mother's right to choose, the son and daughter ensured that their mother's access to alcohol was moderate. Families were not always a safe place for older people and the State Guardian sometimes needed to intervene in abusive situations or to resolve conflicting points of view.

Mitigating risks

Interviewees discussed the risks associated with self-management and ways these can be mitigated. Supporting older people to live at home was thought to bring challenges and risks

for all older people and workers regardless of the management model. The tragic death of Ann Maree Smith[13] was referred to several times to highlight how traditional provider managed supports do not guarantee safety. While self-managed supports brought particular risks because people had more independence and control, these risks were seen as manageable with appropriate support. Interviewees spoke of the challenge balancing peoples' rights to build their capacity, have 'dignity of risk' to choose their lifestyle, and their protection and care.

> "I'm a big proponent of giving people 'dignity of risk'. It's a tricky space and I'm trying to find the balance so you're not making it impossible to support people to live in their own homes. We can easily get to the point where we're so paralysed by risk that we can barely support someone in their own home. I think that's always been an ongoing challenge with community aged care… we are trying to support people's safety, not only the client, but also the worker. But there's got to be some common sense in it as well. It's easy to go one way or the other." (Aged care consultant)

The diversity among people receiving home support means that it is ineffective having uniform administrative safeguards applied to everyone. The following sentiments expressed by the NDIS trainer were echoed by others.

> "The diversity of people who receive support .. makes it so hard to have a 'one model fits all'. There are participants who are highly capable of measuring their own personal risk, managing their own support services, and they may have more agency than the support worker who is working with them. But likewise on the other end of the spectrum, when I look at my own family, if I wasn't here, my brother with his intellectual disability and with his two children with a disability, and my two ageing parents who are so burnt out that it's very difficult for them to maintain the level of support that they have for these years. Without me, my industry knowledge, and my ability to help them manage risk, they would be extremely vulnerable to perpetrators of abuse and people who groom. But they would also be just as vulnerable to the kind-hearted service provider or support worker who is well intentioned but crosses every boundary. It's really complex. How do you impose something on everyone that not everyone needs?" (NDIS staff trainer).

Multiple types of risks were identified. These included: lack of information about rights and responsibilities; financial abuse by family members; exploitation by support workers or other services; purchasing sub-standard or overpriced supports and services; receiving inappropriate services; support workers being privy to every aspect of a person's life,

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[13] SA Police investigating death of woman in 'disgusting and degrading circumstances', 15 May 2020. https://www.abc.net.au/news/2020-05-15/police-investigate-death-of-chairbound-woman-in-adelaide/12253326

including their financial details; intrusive uses of surveillance and tracking technologies that are not transparent; overspending the budget; social isolation and overdependence on paid support instead of continuing informal social networks. Some of these risks apply to all home aged care models of support. Interviewees said that strategies to mitigate risks have to be individually tailored and the most restrictive strategies should not be imposed on everyone.

When discussing financial risks, older consumers countered that they had a lifetime of spending their own money and managing risks, and they were savvier and more frugal than bureaucrats and providers purchasing on their behalf. They said they were more likely to purchase useful items compared to what others purchase for them. However, they expected providers to monitor budgets and curtail spending if a consumer mismanaged their budget. Interviewees acknowledged that some people are not good money managers and may not be suited to self-management. Everyone accepted that a degree of oversight is needed when a person has diminishing cognitive abilities, but this should not be overly intrusive. Everyone should have as much control as possible over their life decisions, within the limits of their capabilities.

The government is introducing compulsory 'shift notes' where every worker, including gardeners and trades people, will submit notes to the provider after every service to an aged care consumer. The notes will flag problems when observed with the aim of mitigating risks. However, interviewees viewed this strategy with alarm. Consumers saw this as an invasion of their privacy with unqualified people being asked to assess their wellbeing.

> "*It goes back to this terrible ageism and paternalism that we're going to look after every aspect of your life, and you can't query it. We'll tell you what is going to happen.*" (Consumer)

Personal & social connections

Isolation and neglect were seen as threats to people's wellbeing. Numerous interviewees spoke of the importance of older people having family and friends to support them. References were made to Anne Marie Smith, mentioned above, who died of neglect by her worker and provider. Being isolated from her community, no one noticed her absence.

Formal 'circles of support' were considered excellent in fostering social connections, overcoming isolation, providing oversight, and preventing abuse. Circle members were family and friends who volunteered their time because they were committed to the welfare of the older person. The size and functioning of 'circles of support' varied greatly and depended upon the needs of the older person and their social circumstances. Preferably they included non-family as well as family members and provided some external oversight. While some circle members attended planning meetings, others shared social activities. They contributed to the older person finding purpose and meaning in life. The voluntary involvement of circle members contrasted with paid supports.

Not everyone had the social capital needed to create a 'circle of support'. A related strategy mentioned was identifying two or three people who knew the older person well and could commit to having regular contact and providing oversight. These might be a family member, a friend, or a professional.

> " [I could] give permission to ring my daughter, my doctor, and my pharmacist….
> [They] would have a pretty good handle on my wellbeing. It would be different for
> different people". (Policy analyst)

While this strategy was widely encouraged, one provider cautioned about making it mandatory. Some people who successfully self-manage had one but not three people who knew them well. Another interviewee cautioned that some people chose to be social isolates.

The provider mentioned above who had face to face annual review meetings, actively communicated with the consumer's family, health professionals, and community contacts, with the consumer's permission. The provider facilitated social connections to prevent isolation.

> "The coordinators try and link the older people with their community, so they are not
> isolated at home… you're talking to the customer about their likes and their dislikes,
> and what they like to do… If somebody said they love reading, [I ask]' 'how would you
> feel about me linking you into a book club? … A support worker would take them to
> club paid out of the package." (Provider)

People were viewed as social beings and not isolated individuals who could purchase all necessary support from the marketplace. While family members were a primary source of support for many people, not everyone had a family. Having broad social connections beyond the immediate family was thought to contribute to positive wellbeing.

> "I think it's unrealistic saying that one relationship is going to fulfil all your needs and
> make sure that you're protected, whether that relationship is with a provider, a
> family member, or one significant other. One is not enough. The only way these
> things can work is if you've got a circle of care, a care team." (Daughter self-
> managing mother's package & self-managing service provider coordinator)

These sentiments were echoed by others. Many people interviewed wanted aged Home Care Packages to facilitate community engagement.

> "People became even more isolated during COVID. Individualised funding and
> individualised support have further isolated people unfortunately because
> everything's decentralised. People are doing stuff one to one more than coming
> together as groups. But I do honestly believe that we can return to a place where we
> reconnect people and help people re-establish their circle of support." (NDIS staff
> trainer)

Interviewees wanted care managers, coordinators, planners, providers, and support workers to be more aware of the critical role social networks play in maintaining mental and physical health and reducing the risks of isolation and neglect.

Lesley Bryce, Founder of Bell Cares Inc, coordinated aged care services in Bell, a small rural town in Queensland. She was engaged by Trilogy, who was the registered provider for all the people she supported. Lesley described how she used a shop front to host community gatherings, foster social networks, and enhance people's well-being. She replicated this model in other towns.

> "What I dream is that communities are holistic. It's almost something that happens organically. If we didn't have a street frontage where people can pop in, I'm sure we would operate differently. People are looking for that connection. They really do come seeking it. We have great numbers at our morning teas, or any event, and they bring friends… It creates a lot of extra work for us, but that's the nature of the model. I think it's a community model." (Aged care coordinator)

The social connections Lesley and her staff created provided her with information about the wellbeing of their consumers and opportunities to recruit support workers. *Bell Cares Inc* is discussed further below in relation to the workforce.

Information and support

A common theme throughout the interviews was the need for consumers and workers to have access to information and support. This included information about rights and responsibilities, resources, and statutory regulations associated with self-management. Having access to information about regulations and resources was seen as critical to making informed decisions. They wanted support to be available as required. One provider offered online courses and all three providers offered telephone assistance. Closed Facebook pages for consumers and others for support workers were a useful source of information and peer support for some people. Differing views were expressed as to whether all support workers needed minimum qualifications or whether short courses relevant to the consumer's situation were sufficient in some circumstances. Most interviewees thought that workers should undertake courses informing them about consumer's rights, their vulnerability, abuse, neglect, violence, reportable incidents, and restrictive practices. Some insisted that information alone was not enough. Workers had to understand and be committed to principles of self-determination and person centred practice.

One support worker felt strongly that all consumers and support workers need face-to-face support. She said,

> "I think there needs to be a mandated training period for workers… The consumer and their carers need to be educated about the types of support they can get… There are already resources available… I don't know if families have the time to look at these resources… [They need] an independent service to contact and actually have a person come out and have a conversation or discussion with them,… [like] local area

coordinators and support coordinators. Not just for self-managed participants, but across the board". (Support worker)

Another support worker had a different point of view. This worker wanted training to be available when required and be relevant to the task at hand. Some workers with no training were thought to provide excellent service while others with certificates did not. The worker said,

> *"It's tricky how you balance someone who is value-driven, provides a very good service but has no certificates. There is a danger in having everything certified, particularly where people aren't needing a clinician... Rather than thinking that one kind of person can provide everything, be open to different supports for different aspects of the person's situation."* (Support worker)

Some providers and online platforms that connected support workers and consumers provided online orientation courses and facilitated Facebook peer support groups. These groups were helpful for some workers, but not for others. One manager said,

> *"The level of sophistication and understanding about their roles has tripled in the last two years. These guys are savvy as. And what's really interesting is they support each other."* (Manager, online platform connecting support workers and consumers)

Uniformly, interviewees argued strongly that assessors, coordinators, and case managers need to be well informed and highly skilled at assessing needs and passing on relevant information. They were not viewed as administrators following standard procedures. They needed high level skills to understand each person's social background and current situation, their physical and psychological well-being, and their aspirations. Interviewees had mixed good and bad experiences with assessors and coordinators.

Workforce

Expanded pool of workers

Interviewees spoke of self-managed support expanding the pool of available workers. This was because consumers tapped into informal networks and recruited people who would not register with a traditional provider. Online recruitment websites also widened the pool of workers. Often the workers offered part-time services and fitted their work around other life commitments such as their family, another job, studies, or semi-retirement.

Many support workers interviewed did not want full-time work. One support worker was an award winning author who supported two NDIS participants with a vision impairment. She had expertise working in this area. Her support work supplemented her fluctuating author's income. Another support worker was an enrolled nurse in her 50s who registered with *Mable* and offered social support. She no longer wanted the responsibility of dispensing medications, and her physical constraints limited her ability to provide personal care. She was in demand to assist people attend social events and appointments. She gained

considerable satisfaction from developing close caring relationships with those she supported.

An online platform manager said:

> "*I think potentially we have a big, untapped resource… I know [government] have just changed the amount of work that people can do when retired and on a pension. Think about all those people who can't afford to retire. It's not the old thing of retire and volunteer any more. People can't afford that and need to keep working. So there's a huge, untapped workforce with years and years of experience in different areas that we can bring into the care economy*". (Manager, online platform connecting support workers and consumers)

Bell Cares Inc demonstrated how support workers can be recruited from the general population when they are approached personally. As mentioned above, *Bell Cares Inc* is in Bell, a small rural Queensland town where staff coordinate support for older people who are registered with the provider *Trilogy* and self-manage. The small town had no aged service provider and no support workers. *Bell Cares Inc* had three staff, including a registered nurse.

In this small town where most people knew each other, *Bell Cares Inc* staff personally met all consumers and workers. *Bell Cares Inc* used informal networks to recruit local people to undertake work appropriate to their skills, qualifications, and interests. The coordinators carefully matched consumers with students, mothers with children at school, semi-retirees, and anyone with appropriate interpersonal skills who was interested in helping older people. Tasks were often social support such as driving people to appointments, light domestic work, home maintenance, and gardening. Workers were usually engaged through the online platform *Mable. Mable* provided insurance cover, ensured that police checks and qualifications were verified, and managed payroll services. Consumers paid Trilogy and Mable a fee from their aged Home Care Packages. A wide range of people were recruited who would not have registered with a traditional provider for full-time work. The benefits included workers gaining an income that circulated around the town.

> "*That's what works so well. You have somebody who's been doing that as a volunteer and getting no money for it, and there's no insurance. I say to them, 'register yourself with Mable, and we can actually then give you properly paid work and properly insured work'. Everyone's happy…. That's creating more work [in the country town].*"
> Manager (*Bell Cares Inc*)

While the *Bell Cares Inc* model was widely lauded for creating support where none existed previously, some interviewees questioned aspects of the model. They questioned whether informal, voluntary community networks were being replaced by commercial relationships. They also questioned Mable's competence in checking qualifications and providing workers with insurance. These concerns are noted but are outside the scope of this study.

Support worker benefits

Choice and control

Support workers valued the flexibility, choice, and control they had working as independent contractors for self-managing consumers. Many had previously worked for traditional providers where they had little control over their work. They preferred to select their consumers and negotiate their duties.

> *"I would never go back. I'm my own boss. And I like the way that I interact with my consumers. If I get a consumer and they don't like me, and I don't like them, we just don't get on, it's okay to say that, and find somebody else, and for them to find someone that suits their needs better. Whereas with an agency you don't have that flexibility… and you travel (long) distances… but you don't get paid for the travel time… they expect you to do 4 or 5 jobs in one day. How can you give the best of your care and the best for them? When you're rushing you can't."* (Support worker)

Support worker challenges

Support workers spoke of the challenges and risks they faced as well as the benefits. They sometimes felt unsafe in peoples' homes. This occurred both when working for an agency and as an independent contractor. Most said they were ready to walk away if ever threatened. One highly experienced support worker said,

> *"When you're in someone's home you're feeling a little bit vulnerable and you're looking for your escape outside. With dementia people it's a little bit different because they don't know what they're doing so you're a bit more tolerant… I always felt I could walk out... I'm a pretty strong person when it comes to stuff like that. But if it's somebody who is young and inexperienced. They're not going to know how to handle that. You need to think about young women in there. Maybe better to have a man."* (Support worker)

Some workers felt obligated to work unpaid hours. The support worker quoted above, who had been a nurse assistant, put considerable unpaid time into planning social activities for her consumers. She worked part-time and said it would not be possible to maintain her high quality work if she worked full-time. While her income was helpful, her husband was the main breadwinner and she worked mostly for personal satisfaction. She said,

> *"In my opinion, it is now impossible to earn a living wage. It is not possible to work that number of hours and give the quality that's needed"*. (Support worker)

Workers tended to work unpaid hours when they first commenced support work, had consumers with unmet needs, and had not learnt to set boundaries. They spoke of learning to manage these demands. One said,

"I was doing well beyond my initial scope of employment. I've learnt a lot about better boundaries, and I would never take on a consumer who [was isolated and] didn't have support around them." (Support worker)

A young worker (24 years) described the dilemmas she faced when consumers did not have sufficient funding and support. She said,

"This client might not have any support. The responsibility was subtly being pushed onto me. Should I come more often, come every day?...I did try to connect them with other support workers but for different reasons they didn't follow through. I felt a bit trapped." (Support worker)

This support worker rang the platform she worked for and sought advice. Although their telephone assistant reassured her that she was doing all that was possible, she did not get the support needed to resolve or come to terms with her dilemmas. This support worker was also concerned by the lack of oversight given to her work and the consumer's wellbeing. She said,

"It's all on a trust basis that the support provided is actually of a high quality and not putting the client at risk… I feel there is a flow on effect that makes the worker vulnerable. No one is checking. There is trust that I'm doing a good job. If the family didn't have experience and know what to expect from a worker or have much control over it, then that would definitely be placing the individual at risk." (Support worker)

Younger workers and those from non-English speaking backgrounds found it more difficult to be assertive than mature workers. They often found it difficult negotiating with consumers. One support worker wanted more hours, regular hours, and a manager to help negotiate with a demanding consumer. She wanted to return to an aged residential service where she had previously worked to have more structure and protection.

Additional challenges and risks mentioned by support workers were lack of information about their rights and responsibilities; lack of knowledge and skills working with older people, especially those with dementia; abuse by consumers and their families; the consumer and their family representative giving opposing directions; consumers becoming overdependent; unsafe workplaces; insecure employment; isolation; lack of support; and providers being slow to pay invoices. The three providers participating in this study were not included in these criticisms. Notably, support workers commented that they had faced the same problems working for traditional providers. They had no additional supervision, training, or peer contact, and they were more exposed to risks when continually directed to unknown consumers. They found that selecting consumers and negotiating tasks reduced their risks.

Service providers

Three approved home aged care service providers supporting self-management were interviewed. While sharing aims and philosophies to maximise consumer self-determination, choice, and control, each provider had a different service model. The first

provider used technology extensively for staff training, monitoring care plans and spending, reviewing shift notes and processing invoices. The other providers were less focused on technology and emphasised their personal interface with consumers. The second provider highlighted their 'shared management' model with annual face-to-face care plan review meetings with each consumer. The third provider described their service model as 'offering flexibility to meet diverse needs'. One example of this flexibility was accepting paper invoices delivered by post when consumers did not use computer technology. All three providers offered telephone support to consumers and support workers.

Service provider challenges

Service providers who supported self-management faced multiple challenges. They had to manage consumer expectations while responding to changing regulatory and auditing requirements.

An aged care coordinator spoke about consumer expectations and educating consumers and their families to spend within their budget.

> [The support worker responded to the consumer's request to take them to multiple appointments and outings without consulting the coordinator about the agreement and the budget.] *"The budget was blowing out, so we had to jump in there and tighten the reins. Everybody got upset… Hopefully, you can get families involved and talk sensibly about it. And they can talk to mum and dad. But sometimes, at the end of the day it's mum and dad that go completely rogue"*. (Coordinator)

The government is concerned about the financial sustainability of aged care. Older people are required to contribute more to their living and support costs, and there are more restrictions on home aged care spending. Fiscal concerns are driving many of the legislative and procedural changes. Providers spoke of the changing regulatory environment and challenges faced due to current uncertainties about funding guidelines and exclusions.

There have been discrepancies between requirements from the *Department of Health and Ageing* and enforcement by the *Aged Care Quality and Safety Commission*. One provider spoke of following the Department of Health and Ageing's direction to restrict the range of items allowed to be purchased with aged Home Care Package budgets. One consumer complained to the *Aged Care Quality and Safety Commission* and the purchase was approved. The consumer blamed the provider for imposing unreasonable restrictions.

One approved aged care provider responded to the research questions through the lens of the draft legislation released for review in December 2023 by the Department of Health and Ageing. If, and when enacted, this legislation will govern all aged care services from self-managed Home Care Packages to nursing homes. This provider expressed concerns that the legislation will stifle self-management because of its restrictive rules and emphasis on compliance at the expense of flexibility. Specific concerns included:

- Self-management is not mentioned in the legislation and is not supported in the reforms.
- Full responsibility for all services delivered in the consumer's home will lie with the home aged care service provider and its board members. The provider will be held responsible for everything that happens in the home even when an activity is unrelated to services being provided.
- Consumers will have reduced choice and control, fewer opportunities to be self-determining, and less able to exercise 'dignity of risk' because providers will be held fully responsible and will feel pressured to minimise risks. No allowances will be made for consumers who self-manage and want to share responsibility for their support services and wellbeing.
- Current provider discretion to meet diverse and complex consumer needs will be replaced by rigid compliance requirements.
- There are inconsistences across the complex legislation, standards, and guidelines, which will inevitably lead to provider non-compliance and sanctions being imposed.
- Providers will lose control of their cash flow and financial viability as government will have authority to garnish a provider's bank account for any payment / reimbursement to a consumer deemed non-compliant with program guidelines and regulations.
- Home aged care providers and their board members will exit the industry as they could face sanctions and heavy fines for non-compliance.

Discussion

Over the seven months duration of this study from September 2023 until April 2024, major changes occurred in the aged care sector. In addition to the *Strengthened Aged Care Quality Standards* being released in November and the *Exposure Draft Aged Care Bill 2023* in December, auditors from the *Aged Care Quality and Safety Commission* reviewed many service providers and online platforms and enforced new regulations. This heightened activity results in this report being out of date before it is completed. Although the context is rapidly changing, it is hoped that the findings from this report will make a valuable contribution to shaping the future of home aged care services.

The findings show that self-management can offer significant benefits to older people, their families, and to workers. Although self-management is not for everyone, many people welcome it. The principal attraction of self-management is having greater control over services, particularly deciding who comes into a person's home to provide personal care. Older people are demanding their right to enhance their lives through self-management and to have 'dignity of risk'. They stridently oppose having their rights curtailed. Paying lower management fees and having more funds for support was attractive to many. However, discussions about costs did not elicit the level of passion that was displayed when discussing issues of control, self-determination, and 'dignity of risk'.

Each person's story was complex and unique. A key message from this study is that blanket restrictions on everybody are unwarranted and oppressive. A capable 70 year old does not need the same protections as someone who is frail and has dementia. Skilled assessors and coordinators play a key role in assessing risks and recommending appropriate support and services. Risks can be managed but not eliminated in all home aged services. Agency managed supports bring their own risks because of the turnover of staff. Self-managing with one worker can also bring risks if that worker becomes ill or suddenly leaves the role.

The findings support arguments that traditional aged care services are too inflexible to meet everyone's needs[14]. Rosemary's story presented above will be used to reflect upon the positive features of self-management. Her story illustrates themes shared by others.

Rosemary had excellent family and personal supports and extensive social networks. Her son and her close friend enabled her to avoid moving from hospital to a nursing home. Her friend offered information about self-management, support to register with a suitable provider, and assistance managing invoices until she mastered the administrative procedures. Accessing information and support on a timely basis, having initial support to learn how to self-manage, and having choice and control to make informed choices are important for successful self-management[15].

Rosemary had the advantage of an informal 'circle of support', consisting of her son and her friend, who supported her to make decisions. The importance of having 'natural' supports in self-managed programs is widely recognised across aged and disability services, as is the need to provide education and support[16]. However, families and friends do not always understand person centred practices and can cut across the consumer's right to self-determination. Rosemary was lucky.

While providers require one personal contact in case of an emergency, interviewees suggested that every consumer create a formal 'circle of support', or as a minimum invite two or three people to become actively involved in their planning and oversight and communicate with their service provider. If a consumer has no informal networks, their general practitioner, pharmacist, or other health professional were suggested as contacts. However, their participation would depend on their accessibility, availability, and potential cost. Voluntary family and friends were considered far preferable.

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[14]   Lee, M. (2023). Lifeboat: Disability, humanity and the NDIS. *Quarterly Essay* (91), 1-67. https://search.informit.org/doi/10.3316/informit.299066467911552

[15]   Laragy, C., David, C., & Moran, N. (2016). A framework for providing information in individualised funding programmes. *Qualitative Social Work, 15*(2), 190-208. doi:10.1177/1473325015589402

[16]   Fleming, P., McGilloway, S., & Barry, S. (2016). The successes and challenges of implementing individualised funding and supports for disabled people: an Irish perspective. *Disability & Society, 31*(10), 1369-1384. doi: 10.1080/09687599.2016.1261692

Rosemary was in the fortunate position of knowing a trusted person who became her support worker when she needed assistance. Using her aged Home Care Package to contract this support worker six hours a week enabled her to remain living at home over the past five years. Rosemary's experience counters the arguments put by unions to the *Royal Commission into Aged Care Quality and Safety* (2021) and by *Per Capita* (2022) discussed above that all support workers should have full time, permanent positions, and job security. Although her support worker was not interviewed, Rosemary reported that he gained qualifications as a brick layer while supporting her. Support workers who were interviewed gave similar accounts of combining their work with other lifestyle choices. Full-time work was not a viable option for many support workers interviewed. Part-time work suited the workers and expanded the pool of workers.

Rosemary's story contradicts Per Capita's (2022) assertion that contracted workers will focus on discrete tasks and not develop a trusting and continuous relationship with their consumers. The opposite was found to be true. Close, long-term working relationships were often developed between consumers who self-managed and their workers.

Rosemary and all other consumers interviewed mentioned the benefits of paying lower administrative fees and having more funds to purchase services and supports. As important as economic savings were because aged Home Care Packages were often insufficient to meet needs, having flexibility and control were seen as bigger advantages. Rosemary felt affirmed and empowered managing her finances and choosing her support worker.

Other consumers also spoke of their increased skills and satisfaction managing their support. All self-managing providers offered telephone help lines, and some had online training videos. However, overall, this study identified few capacity building opportunities. It has been found elsewhere that consumers need considerable help initially and less as they become familiar with procedures[17]. For self-management to be widely successful, more capacity building opportunities are needed. Consumers need to understand the philosophy of self-management, the mechanisms of the aged care system, and their obligations and responsibilities. A consultant recommended that a government funded 'aged care self-management hub' provide this information.

Most consumers and their families were able to recruit support workers when needed. They used a range of methods that included recruiting through online platforms, they advertised widely, and used personal networks. The targeted sample in this study was particularly resourceful and not representative of the wider consumer population who might have more

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[17] Laragy, C., & Vasiliadis, S. D. (2022). Self-managed aged home care in Australia –Insights from older people, family carers and service providers. *Health & Social Care in the Community, 30*(5), e2518-e2529. doi:10.1111/hsc.13695

problems recruiting staff. However, Rosemary was not totally spared the challenge of finding workers. She could not find a suitable occupational therapist.

The challenges and risks reported by support workers leaves no room for complacency. While highly experienced support workers felt confident managing any risks that arose, younger and more vulnerable workers wanted more support. Although training was considered important, having access to personal support when needed was more highly valued. Interestingly, self-managed contract work presented fewer risks for some workers than working for traditional providers. Traditional providers continually directed them to unknown consumers, and they had no supervision or peer contact. They felt much safer selecting their own consumers and negotiating their tasks.

On 15 March 2024 the Fair Work Commission announced that minimum wages of aged care workers will increase by up to 28.5 per cent[18]. This will contribute to aged care workers gaining decent working conditions and a living wage. A positive aspect of contracted self-managed arrangements is that workers can negotiate above minimal rates. Nonetheless, workers from some ethnic or disadvantaged backgrounds find it difficult to assert their rights. Having adequate minimum pay rates is important.

Most support workers in this study preferred self-managed contracted work to traditional agency work because they had more choice and control over their work arrangements. Nonetheless, work environments were complex and demanding and every worker had different needs, expectations, and skills. The report from *Safe Work Australia* that community and personal service workers had the second-highest injury incidence rates nationwide in 2020-21[19] focuses attention on their safety. They did not distinguish between agency employees and contracted workers.

One worker from a non-English speaking background was trying to return to residential aged care where she had worked previously. She lacked the skills to negotiate with her consumer and she wanted a manager to intervene. This shows that one set of conditions will not suit everyone. Different options are needed to match workers, consumers, and work environments. Another important finding is that support workers face risks and challenges because consumers are under resourced. Some workers were torn between working the contracted hours and donating unpaid hours because extra support was clearly needed. This dilemma was one of the most stressful challenges many support workers faced and will continue while insufficient resources are allocated.

In summary, this study demonstrated that self-management is a viable option for older people and support workers. Consumers need appropriate information and support from

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[18] Fair Work Commission https://www.fwc.gov.au/documents/decision-summaries/2024fwcfb150-summary.pdf

[19] Safe Work Australia. (2022). *Australian workers' compensation statistics 2020-2021*. Page 17.
https://www.safeworkaustralia.gov.au/doc/australian-workers-compensation-statistics-2020-2021

well informed and highly skilled assessors, case managers, and coordinators to navigate complex service systems. Their lives are complex with health and abilities often compromised. Ready access to reassessment and support is essential. People who self-manage treasure the flexibility and extended range of options available, having more funds to purchase services, and they report improved wellbeing. Support workers also preferred the choice and flexibility they had as a contractor working for self-managing consumers. However, younger and more vulnerable workers needed more support. It remains to be seen if the new legislation and guidelines will support self-management and what opportunities will exist for consumers and workers.

Acknowledgements

Appendix A: HREC approval letter

Office of Research Ethics and Integrity
Human Ethics Application Approval

01/09/2023

ATTENTION: DR Carmel Laragy

1660 - Social and Political Sciences
1000 - Arts
The University of Melbourne

Reference Number: 2023-27262-44561-5
Project Title: Stakeholder views on optimising self-managed home support services

Dear DR Carmel Laragy,
Your application for amendment to your project has been approved on the basis that it meets the requirements of the National Statement on Ethical Conduct in Human Research (2007, Updated 2018).

Any original conditions attached to your project remain applicable. It is your responsibility to ensure that all people associated with the project are made aware of what has been approved, and that other relevant approvals are obtained before work on this project begins.

Please contact us via the Correspondence tab if you have any questions or if you require further assistance.

Kind regards,

MS Yasi Saninejad

Research Ethics Officer

Human Ethics Team
Office of Research Ethics and Integrity | Research, Innovation & Commercialisation
Level 5, Alan Gilbert Building, 161 Barry Street, Carlton
The University of Melbourne, Victoria 3010, Australia
E: saninejadf@unimelb.edu.au

Summary Details for the Approved Human Ethics Project:

Project Title: Stakeholder views on optimising self-managed home support services
Reference Number: 2023-27262-44561-5
Approval Date: 01/08/2023
Expiry Date: 01/08/2026
Responsible Human Ethics Committee HASS 2
Project Supervisor DR Carmel Laragy
Other Investigators PROF Keith McVilly
External Investigators

Documents Table:

Document Type	File Name	Date	Version
Participant distress protocol	Distress management protocol TA305251 Laragy 31.7.23 V3	31/07/2023	3
Questionnaire(s) and/or survey instrument(s)	Questions TA305251 Laragy 31.7.23 V3	31/07/2023	3
Other	Responses to reviewers comments 31.7.23	31/07/2023	1

Document Type	File Name	Date	Version
Consent form	Consent Form TA305251 Laragy 31.7.23 V3	31/07/2023	3
Recruitment materials	Invite emails to participants TA305251 Laragy 31.8.23 V4	01/09/2023	4
Plain Language Statement (PLS)	PLS TA305251 Laragy 31.8.23 V4	01/09/2023	4
Recruitment materials	Invite emails to participants TA305251 Laragy 31.8.23 V4	01/09/2023	4

Conditions of Approval:

Research projects are usually approved for 1 year (to the anniversary date of the approval). Projects may be renewed yearly upon receipt of a satisfactory annual report, for up to a total of three years. If a project is to continue beyond three years, an extension of one year is available, up to a total of 5 years (3+1+1). If a project extends beyond five years, a new application must be submitted. Please contact our office if you require assistance with this.

Please note that the following conditions apply to your approval. Failure to abide by these conditions may result in suspension or discontinuation of approval and/or
disciplinary action.

1. **Limit of approval:** Approval is limited strictly to the research as submitted in your Project application.
2. **Variation to project:** Any subsequent variations to the Project must be notified formally to the Committee as an Amendment. These must be approved before they are implemented. If the Committee considers that the proposed changes are significant, you may be required to submit a new application.
3. **Incidents or adverse events:** Researchers must immediately submit to the Committee an incident report for any incident that could affect the ethical acceptability of the project, including adverse effects on participants or unforeseen events. Failure to do so may result in suspension or cancellation of approval.
4. **Annual reports and monitoring:** All projects are subject to monitoring at least annually. An annual report must be submitted each year on the anniversary of project approval (progress report), and at the conclusion of the project (final report). If an annual report is not submitted, the conditions of approval for that year will not have been met.
   FOR PROGRAM APPLICATIONS: Please ensure that you attach all Student Proposal Forms (to be completed before each student begins their research) to your annual report submission.
5. **Auditing:** All projects are subject to auditing at any time by the University.

Appendix B: Plain Language Statement

School of Social and Political Sciences
Faculty of Arts

Project:
Stakeholder views on optimising self-managed home support services

Project Supervisor: Dr Carmel Laragy
Tel: 0427 982298. Email: carmel.laragy@unimelb.ed.au
Project Oversight: Prof Keith McVilly,
Tel: +61 3 8344 5366. Email: Keith.McVilly@unimelb.edu.au

Introduction

Thank you for your interest in participating in this research project. The following few pages will provide you with further information about the project, so that you can decide if you would like to take part in this study.

Please take the time to read this information carefully. You may ask questions about anything you don't understand or want to know more about.

Your participation is voluntary. If you don't wish to take part, you don't have to. If you begin participating, you can stop at any time.

What is this research about?

The purpose of this research is to investigate how to deliver self-managed support services safely and effectively.

Thirty interviews will be conducted with people associated with self-managed services. The participants will be:

• Older people who self-manage or their representative
• NDIS participants who self-manage or are plan managed
• Support workers employed under self-managed arrangements
• Service providers who support older people to self-manage
• Online recruitment services, aged care navigators, financial support services, NDIS planners or coordinators
• Policy makers

All information gathered from service users and support workers will be reported anonymously. Other interviewees will be asked if they want to be identified.

What will I be asked to do?

Should you agree to participate, Dr Carmel Laragy will interview you once using Zoom online or by phone by for about 30-60 minutes. She will ask your opinion about: i) any benefits that self-

managing a support package gives to the person or their support workers; ii) any risks that self-managing a support package gives to the person or their support workers; iii) strategies to minimise any risks identified; and iv) better ways to maximise service quality and outcomes. The interview will be recorded on Zoom or on the phone and the audio file will be transcribed.

What are the possible benefits?
It is intended that the information gathered in this study will be used by providers, support services, and policy makers to design and implement self-managed services to give maximum benefits to service users and their support workers.

What are the possible risks?
Some people may feel distressed discussing their personal situation and the inadequacy of support services. Should that occur, Dr Laragy will seek ongoing support if required. No other risks are likely.

Do I have to take part?
No. Participation is completely voluntary. You can withdraw at any time. Data collected can be withdrawn until it is combined with other data and analysed anonymously.

Will I hear about the results of this project?
A report on the findings of this study will be publicly available and emailed to all participants. If a participant does not use email, a copy can be posted.

What will happen to information about me?
All information will be reported anonymously. The study will interview people who are self-managing and support workers from across Australia. It is unlikely that anyone could be identified. If there is any special identifying feature in a person's story, the person will decide if they want this to be revealed. Other people interviewed will decide if they want to be identified or have their views presented anonymously.

When interviews are recorded on the virtual meeting platform Zoom, visual and audio recordings are saved. Once the audio recording is transcribed, the visual and audio recordings will be deleted. The transcriptions will be kept on a secure University of Melbourne server and destroyed five years after the final report is published. The transcripts may be included in future research into self-managed services. Only University of Melbourne researchers would see the deidentified transcripts.

Who is funding this project?
This study is funded by *Empowered Ageing,* a provider that specialises in supporting people to self-manage their aged care packages. *Empowered Ageing* has engaged *The University of Melbourne* to provide an independent study of self-management and make recommendations for improvements.

Participants in the study who are self-managing a support package, their representative, and support workers will be given a $50 prepaid Visa gift card in appreciation of their time, as is the practice in aged and disability research projects.

Where can I get further information?

If you would like more information about the project, please contact the researchers:

Dr Carmel Laragy, Email: carmel.laragy@unimelb.edu.au, Mob. 0427 982298.

Prof Keith McVilly, Email: Keith.McVilly@unimelb.edu.au, Tel: +61 3 8344 5366.

Who can I contact if I have any concerns about the project?

This project has human research ethics approval from The University of Melbourne, project number: TA305251. If you have any concerns or complaints about the conduct of this research project, which you do not wish to discuss with the researchers, you should contact the Research Integrity Administrator, Office of Research Ethics and Integrity, University of Melbourne, VIC 3010. Tel: +61 3 8344 1376 or Email: research-integrity@unimelb.edu.au. All complaints will be treated confidentially. In any correspondence, please provide the name of the researchers and/or the name or ethics ID number of the research project.

Consent Form

School of Social and Political Sciences
Faculty of Arts
Project: Stakeholder views on optimising self-managed home support services
Project Supervisor: Dr Carmel Laragy
Tel: 0427 982298. Email: carmel.laragy@unimelb.edu.au
Project Oversight: Prof Keith McVilly,
Tel: +61 3 8344 5366. Email: Keith.McVilly@unimelb.edu.au

Name of Participant: _____

1. I consent to participate in this project, the details of which have been explained to me, and I have been provided with a written plain language statement to keep.
2. I understand that the purpose of this research is to investigate how to deliver self-managing support services safely and effectively.
3. I understand that my participation in this project is for research purposes only.
4. I acknowledge that the possible effects of participating in this research project have been explained to my satisfaction.
5. I understand that the aged care provider *Empowered Ageing* has funded this independent study.
6. In this project I will be required to participate in only one online interview of 30-60 minutes duration.
7. I understand that my interview will be audio and video recorded on Zoom or on the phone and the audio will be transcribed.
8. I understand that my participation is voluntary and that I am free to withdraw from this project anytime without explanation or prejudice and to withdraw any unprocessed data that I have provided.
9. I understand that the data from this research will be stored at *The University of Melbourne* and will be destroyed 5 years after publication.
10. The anonymous data collected may be included in future research into self-managed services.
11. I have been informed that the confidentiality of the information I provide will be safeguarded subject to any legal requirements; my data will be password protected and accessible only by the named researchers.
12. I understand that I can give my written consent to this form in one of three ways.
    i) I can insert an electronic signature and date below, and email the form to Dr Laragy, or
    ii) I can print, sign and date, and scan this form and email it to Dr Laragy, or
    iii) I can email Dr Laragy saying, "I have read the attached Ethics Consent Form and I consent to participating in this study". The unsigned consent from must be attached to the email.

13. I understand that after I give my consent and return this consent form, the statement of my consent will be retained by the researcher.

Name of Participant: _____

Appendix D: Interview Guide

Questions for semi-structured interviews

An action research approach will be taken where ideas presented in earlier interviews may be discussed in subsequent interviews.

Questions for self-managing aged care clients & NDIS participants

1. Why did you choose to self-manage / plan-manage your support package?
2. What services and supports do you purchase?
3. How do you find and engage the support workers and other contractors you use?
4. How easy or hard is it to find and engage the contractors and services you need?
5. How long have you been self-managing or plan managed?
6. Is your funding adequate to meet your needs?
7. Are you purchasing the services outlined in your plan?
8. What tasks are required of you to self-manage / be plan-managed?
9. Are guidelines and responsibilities clear?
10. Does self-managing / being plan-managed bring challenges or risks?
11. Is support available if needed to self-manage / plan-manage your package?
12. Are there ways that self-management / plan-management could be improved?
13. Any other comments?

Questions for support workers contracted under self-managed / plan managed arrangements

1. What are your employment arrangements? Contracted by client? Employed by agency? Other?
2. Can you choose who you support?
3. Why do you work for someone who self-manages / is plan-managed?
4. Do you like your work as a support worker?
5. How many hours per week do you work?
6. Would you like more work hours?
7. How long have you worked for people who self-manage / are plan-managed?
8. Have you worked under other arrangements?
9. Are there advantages working for someone who self-manages / is plan-managed compared to other arrangements?
10. Are there disadvantages working for someone who self-manages / is plan-managed compared to other arrangements?
11. Have you ever felt unsafe working as a support worker?
12. Any suggestions for improving your working conditions?
13. Any other comments?

Questions for aged care service providers

1. Do you provide traditional agency managed supports as well as support to people who self-manage?
2. How long have you supported people to self-manage?
3. Why have you chosen to support people who self-manage?
4. Are there advantages for older people who self-manage compared to agency managed supports?

5.   Are there disadvantages for older people who self-manage compared to agency managed supports?
6.   Do you exclude some clients? If yes, what are your exclusion criteria?
7.   Are there times when you think a person is no longer able to self-manage? If yes, how do you manage this?
8.   The *Royal Commission into Aged Care Quality and Safety* (2021) discouraged self-management because they thought it was too risky for vulnerable, older people. What is your opinion about this?
9.   Are there major risks for older people who self-manage? If yes, how do you mitigate these risks?
10.   Does your service face major challenges and risks supporting people who self-manage? If yes, how do you mitigate these challenges and risks?
11.   You have to comply with the Aged Care Quality Standards. Are they fit for purpose?
12.   How easy or difficult is it for you to comply with the regulations requiring you to monitor payments, ensure that spending is within approved guidelines, and that spending in accord with the person's plan?
13.   Any suggestions for improving self-managed support services?
14.   Any other comments?

Questions for aged care navigators, online recruitment services and financial support services
1.   Please describe the service you provide.
2.   Do you work with older people who self-manage and/or NDIS participants who self-manage or are plan-managed?
3.   How long have you provided this service?
4.   The *Royal Commission into Aged Care Quality and Safety* (2021) discouraged self-management because they thought it was too risky for vulnerable, older people. What is your opinion about this?
5.   Are there major risks for people who self-manage / are plan-managed? If yes, how can these risks be mitigated?
6.   Are there major challenges and risks for your service supporting people who self-manage or are plan-managed? If yes, how do you mitigate these risks?
7.   Do you exclude some clients? If yes, what are your exclusion criteria?
8.   Are you subject to aged care and disability quality and safety regulations? If yes, are they fit for purpose?
9.   Any suggestions for improving self-managed or NDIS plan managed support services?
10.   Any other comments?

Questions for NDIS planners or coordinators
1.   Please describe your NDIS role.
2.   How long have you been in this role?
3.   Do you have selection criteria and discretion to decide who you work with?
4.   Approximately 25% of NDIS participants self-manage and many more are plan-managed. Are there selection criteria for allowing participants to self-manage or plan-manage?
5.   Why do people choose to self-manage or be plan-managed?

6. Are there challenges and risks for people who self-manage and plan-manage compared to NDIA-managed services? If yes, how can these risks be mitigated?
7. If a person is not coping with self-managing or being plan-managed, how do you manage this?
8. Are there advantages for support workers who are contracted directly by people who self-manage or are plan-managed?
9. Are there disadvantages for support workers who are contracted directly by people who self-manage or are plan-managed?
10. Any suggestions for improving self-managed or plan-managed services?
11. Any other comments?

Questions for aged care policy makers
1. Please describe your role.
2. The *Royal Commission into Aged Care Quality and Safety* (2021) discouraged self-management because they thought it was too risky for vulnerable, older people. What is your opinion about this?
3. Are there selection criteria for allowing people to self-manage? If yes, are they appropriate?
4. How would it become known if a person is no longer able to self-manage?
5. Are there any advantages for support workers who work for people who self-manage?
6. Are there any disadvantages for support workers who work for people who self-manage?
7. Are the Aged Care Quality Standards fit for purpose? Is it appropriate to have the same standards for residential services and self-managed service providers?
8. Any suggestions for improving self-managed services?
9. Any other comments?