



# Accentuating the positive: Consumer experiences of aged care at home

April 2018

**National Seniors**  
Australia



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## EXECUTIVE SUMMARY

### Background and purpose

National Seniors Australia was contracted by the Australian Government Department of Health to document consumer experience of aged care services delivered in the home and community. The purpose was to inform the Aged Care Workforce Strategy Taskforce, which has five imperatives:

1. Why this industry matters;
2. Industry leadership, mindset and accountability;
3. Workforce organisation and education;
4. Attraction and retention of workers; and
5. New models of care and practice coming from research and development.

To address these imperatives National Seniors has undertaken four components of work reported here:

1. A national survey with 4,536 responses of a population 50+ years of age, opened 14 February and closed 4 March 2018, which provides the data for an 'evidence-based framework' of consumer views;
2. Textbox comments from people in the survey providing and receiving home care and home support, which allow us to avoid over-emphasizing positive or negative biases from data gathered in interviews and consumer stories that have a much narrower population coverage;
3. Interviews with aged care clients and their current direct care providers from range of backgrounds: large, boutique, major city, and rural and remote locations; and
4. Consumer stories of their journey in aged care, usually from care at home to nursing home admission.

### Data and Methods

The National Seniors study reported here was an online survey that collected data from Phase 1 of the National Seniors Social Survey (NSSS) (Wave 7) conducted between 14 February 2018 and 4 March 2018 by National Seniors Research Director, Professor John McCallum. The study was approved by the Bellberry Human Research Ethics Committee of South Australia on 31 January 2018, application number 2017-12-981. Bellberry is an NHMRC accredited HREC.

Phase 1 of the survey asked members about their experiences of aged care delivered in the home. A total of 47,280 National Seniors Members residing in all states and territories of Australia with an email address were invited to complete the survey. A total of 4,536 surveys were completed, a response rate of 9.6 per cent.

Aged care journey stories from National Seniors members were collected by email and post between December 2017 and January 2018. Interviews of clients of home support and care services and their personal care workers or care managers were conducted from 5 to 19 March 2018.

## Key Findings

For experiences of receiving home support and home care services:

- 87 per cent of respondents agreed that personal care workers treated the household with respect (excluding “Not applicable” responses, 95.7 per cent agreed);
- 63 per cent agreed that the personal care and support met the clients’ needs in areas such as clinical care, showering, and household services (excluding “Not applicable” responses, 87.2 per cent agreed);
- 68 per cent agreed that personal care workers explained things to the client (excluding “Not applicable” responses, 87.1 per cent agreed);
- Almost three quarters agreed that workers know what they are doing and are well trained (excluding “Not applicable” responses, 82.7 per cent agreed);
- Just over half agreed that the person receiving care was encouraged to do as much as possible independently, and shown how to do it (excluding “Not applicable” responses, 78.5 per cent agreed);
- 67 per cent agreed that the service organisation was well run (excluding “Not applicable” responses, 77.6 per cent agreed);
- Less than half agreed that care is well-coordinated and connects with other health services, e.g. physiotherapy, podiatry, out-patients (excluding “Not applicable” responses, 68.0 per cent agreed);
- The average agreement rate across these 7 items was 65 per cent (excluding “Not applicable” responses 82 per cent average agreement) indicating a strong positive accent to consumers experiences;
- Finally 39 per cent agreed that ‘things could be done better or differently’ (excluding “Not applicable” responses, 49.5 per cent agreed) and comments indicated their concerns.

In addition

- 31 per cent agreed that Consumer Directed Care was helping to meet more of their needs now (excluding “Not applicable” responses, 72.4 per cent agreed)

A range of issues were commented on regarding services delivered at home, including:

- Services being delivered at times or in ways that were inconvenient to the client;
- A lack of continuity of care for dementia patients and poor training for dementia care;
- The frustration caused by WHS constraints on cleaning, and poor cleaning services;
- Waiting too long to be assessed, and having to accept a lower level package until a higher one became available;
- Lack of duty of care and the occurrence of theft;
- Poor communication from the provider, and poor administration of services generally;
- Failures in the delivery of Consumer Directed Care; and
- Poor cross-sectoral care coordination.

For experiences of caregiving:

- Three-quarters indicated that they had the appropriate skills to provide informal care; and
- More than 40 per cent of caregivers stated that their health was affected by their caring duties.

Issues raised by providers of informal (family, unpaid) care in comments included:

- Physical health effects;
- Stress, mental exhaustion and feeling overwhelmed;
- The need for more respite care;
- Having to learn the skills “as you go”;
- Loss of income; and
- Difficulties coping with family dynamics.

For gaps in training and future considerations:

- Training for informal carers remains a priority because of its impacts on health;
- Personal carer, care planning, personal advocacy, and cleaning were among the gaps identified;
- Mandated courses and qualifications need consideration;
- Shorter courses and on-the-job training are also possibilities; and
- Developing a Skills Escalator for the industry could boost labour supply including informal carers seeking to re-enter the workforce.

## Conclusion

This report identifies a high degree of positivity about aged care services delivered in the home, with strong agreement that aged care workers treat the household with respect, know what they’re doing, and are well trained. However, negative consumer experiences and the burdens of informal caregiving came through in comments on particular aspects of care. In the present time of change, listening to expressions of both positive and negative views on home support and home care is the key to creating better services in the future. The consumer voice needs to be the driver for changes in the industry as ‘ageing in place’ becomes increasingly the norm.

Respondents were ambivalent about the benefits of Consumer Directed Care, perhaps due to lack of awareness of the term or understanding of the concept. Clear gaps in care provision were identified in the comments, including care planning and coordination issues, the need for greater communication from providers, poor cleaning services, the need for more dementia care training, and the lack of respite and support services for informal carers.

New service providers with different models are coming to home services in aged care. It is clear from the evidence gathered in this study that older Australians have a consistent preference for high levels of human contact and communication, which will need to be retained, whatever technological assistance is used.

A number of training initiatives could be considered to improve outcomes, including training for informal carers, mandated courses and qualifications for personal care workers and care managers, increased access to short courses for ongoing skills development, and more targeted on-the-job training.

## Acknowledgements

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# 1. INTRODUCTION

## 1.1 The five Taskforce imperatives

The Aged Care Workforce Strategy Taskforce (ACWST) articulated five imperatives to shape the workforce strategy, which are directly addressed in this report.



*The first – why this industry matters – is about recognising rising consumer demand for ageing services, re-profiling the industry, good governance, and acknowledging it is essential that people want to belong to this industry.*

This first imperative is the major target for this report which provides extensive views of consumers and their needs and reports their experiences and those of their immediate care providers in their own words.

*The second is about securing an agreed view of the role of industry leadership to provide the foundation for securing a sustainable strategy, supported by changes in mindsets (within and outside the industry) and making industry and provider accountability clearer to users of services and the community.*

**Figure 1: ACWST five strategic imperatives**

Industry mindsets and accountabilities are revealed here through the experiences of consumers and care workers at the point of service delivery. There is a particular focus in the report on industry leadership in meeting training needs for existing and emerging skill requirements.

*The third is focused on the industry workforce and the current and emerging education, training and skills development needs, and calls for detailed analysis of the current state to reach informed conclusions on future state.*

Consumers and their immediate service providers have given us clear education and training issues and a lead into a vision for future needs. This need for training also applies to family and friend carers working at home without being paid.

*The fourth is about analysing the factors influencing the employment choices of people from a variety of sources and backgrounds, the steps needed to boost attraction and identifying well-targeted actions to improve retention.*

The negativity in many consumer comments and stories of their service journeys indicates issues that need attention to give workers more positive, flexible employment choices. The importance of good quality skills and training in this context was strongly supported by consumers.

*The last lays the foundation to finding ways to develop, sustain and adjust models of care, implement work practices to support better care outcomes and support workforces with evidence-base or evidence-informed resources and tools.*

Preferred models of care can also be derived from the voices of consumers commenting on different service encounters and different providers. They are also being imagined in new technological developments, which require reflection on what the preferred futures might be.

*For all imperatives, taken together, there needs to be a clear line of sight to what the industry does well. Choices will need to be made on what needs to be encompassed in an industry-wide workforce strategy. Industry leadership and stewardship of a strategy will need to be considered, along with the support role of government.*

To assist with this overall imperative the report provides prevalence data and themed text and interview insights into what consumers receive and expect to get.

## 1.2 Complaints about residential care

Aged care service providers constantly confront negative press and widely held negative community views on aged care services. This is particularly the case when the service journey experience of care at home fades in significance as it reaches its final stage in residential aged care, as reported by National Seniors members in their aged care “journey stories”, for example:

- (1) *In the first 8 months she was in care, I had to spend much of the day with her ... My health suffered enormously with not only worry about my mother’s unmet needs, her loneliness, her lack of adequate psychological care, the quality of food, the focus on profit, always profit.*
- (2) *I found that the employees were the most socially inept and of a very low class. The pay was low and only attracted the worst kind of person.*
- (3) *A senior nurse apologised for inadequate staffing and if you visited early evening, you had to search for someone. It was like a morgue.*
- (4) *I live in dread of being placed in a home ... The food was appalling (cooked off site) and most inmates were lined up in front of the TV all day. My mother would have been better off in gaol. A nursing home is far worse than any other form of incarceration! ... They appear to be simply ways of making money for the owners. I have no expectations of nursing homes in general and hope vehemently that I will die before I ever have to enter one since one’s life is over when one goes in the door.*
- (5) *It seems that nursing homes, whether you are low care, high care or have dementia, are the last stop in the journey of life. Not good enough. I dread the thought of being in such an environment because that is what it is.*

For the providers, bad press and media reports can lead to a reputational management response which doesn't necessarily express a strong community connection or contract with clients. It's true that not all negatives are representative of majority views but, on the other hand, they can be made into valuable guides for improvement.

On the panel discussion, ‘Quality and customer experiences in aged care’ at The Next Phase of Aged Care Reform Conference on 2 November 2017, the Aged Care Complaints Commissioner, Rae Lamb, addressed the issue of complaints by saying that opportunities are being missed in using complaints to improve care. She believes the message is to listen to consumers, make it easier for consumers to complain, and normalise complaints as part of giving a service:

*Complaints are like “the golden hour” – the first hour of responding to a medical emergency is known to be the most effective. Even the best places should be getting complaints. It’s what you do about them that matters (Criterion Conferences, 2017).*

What is needed is to have a positive movement forward. If we are fully aware of the negatives and weak points, ‘reputational management’ by providers can be replaced by a full and open discussion with the community of the relevance of what is being done. Unless the community develops a more positive view of aged care services, it will be very difficult to improve services or people’s levels of service literacy. A milestone for the Aged Care Roadmap (Aged Care Sector Committee, 2016) is the promotion of positive societal attitudes about aged care (Table 1), which doesn’t appear to have made much progress if recent media comment is any guide.

**Table 1: Aged Care Roadmap milestone: promote positive societal attitudes about aged care**

Aged Care Roadmap – a snapshot				
Domain	Short-term (within 2 years)	Medium-term (within 3-5 years)	Long-term (within 5-7 years)	Destination
How do consumers prepare for and engage with their aged care?	<ul style="list-style-type: none"> <li>- Promote positive societal attitudes about aged care</li> <li>- Improve access to information, support services, and advocacy</li> <li>- Co-design consumer strategies</li> <li>- Build a change narrative around social expectation</li> </ul>	<ul style="list-style-type: none"> <li>- Highlight individual benefits of planning early</li> <li>- Support consumer choice by enhancing My Aged Care</li> <li>- Support consumer empowerment base on the co-design process</li> </ul>	<ul style="list-style-type: none"> <li>- Build long term messaging from evaluations</li> <li>- Build My Aged Care to become a core component of a virtual aged care market</li> </ul>	Consumers, their families and carers are proactive in preparing for their future care needs and are empowered to do so
How will the formal and informal workforce be supported?	<ul style="list-style-type: none"> <li>- Clarify the roles of government and providers on workforce matters</li> <li>- Leverage government programmes that will boost workforce supply</li> <li>- Develop an integrated plan for carer support services</li> </ul>	<ul style="list-style-type: none"> <li>- Develop career structures and pathways within aged care and across care and community sectors</li> <li>- Implement actions from the integrated plan for carer support services to support unpaid carers</li> </ul>	<ul style="list-style-type: none"> <li>- Continue to implement actions from the integrated plan for carer support services to support unpaid carers</li> </ul>	A well-led, trained workforce that is adept at adjusting care to meet the needs of older Australians

Without this positive perception of aged care services many important consumer decisions are inhibited:

- People don't want to plan or save for services in later life (McCallum, Maccora, & Rees, Hope for the best, plan for the worst? Insights into our planning for longer life, 2018);
- People, more generally, don't want to be forced to consider future aged care needs, and then end up dealing with care needs when in a time of crisis without any planning (Rees & McCallum, 2017);
- Workers feel they are working in a bad industry and want to move to something better (Aged Care Workforce 2016);
- Attraction is also difficult with the barrier of a negative image of the industry (Aged Care Workforce 2016);
- Abuse and neglect are known to be a greater risk in a negatively regarded consumer and service environment.

This dynamic must be harnessed so that changes move in a positive direction. The negatives are healthy guides for change but the change must be actioned to create the new positive. We need an open and healthy back-and-forth debate to create the dynamic for better services. This dialectical approach to action and knowledge has a strong foundation in classical philosophy.<sup>1</sup>

The different evidence sources collected for this report produced predominantly either positive or negative results, mainly because different types of data collection reveal one or the other. For example:

- The NSSF qualitative evidence shows a high level of satisfaction with the care being received because respondents weigh up their overall experiences and answer accordingly;
- The NSSF (Wave 7) textbox comments (268 for care recipients and 499 for caregivers) contained many negative observations, as well as neutral and positive ones, because respondents chose to comment on some specifics of their care services;
- Eight self-initiated stories of journeys with services are almost entirely negative because these people needed to express their dissatisfaction and disillusionment about experiences of aged care to someone, and the 'journey' being described mostly resulted in residential care;
- The 19 interviews with clients and care providers are generally positive, with the most positive comments coming from boutique providers and their clients.

This variation in sentiment could be due to the wide variety of survey respondents' providers compared to the narrow range for one-on-one interviews. The anonymous nature of the online survey possibly provided a forum for negative experiences to be expressed in text boxes, despite responses to targeted questions being mostly positive. Undoubtedly, consumer experiences of home services over many months or years can be widely variant, thus, it could also be that respondents rated their overall experiences as good when answering qualitative survey questions, but then commented on specific instances of negative experiences in the text box space.

<sup>1</sup> The dialectical approach has a sound philosophical base in Platonic debates and the dialectical philosophy of G.W.F. Hegel who writes that the result of this: "is a new concept but one higher and richer than the preceding - richer because it negates or opposes the preceding and therefore contains it, and it contains even more than that, for it is the unity of itself and its opposite." (SL-dG 33; cf SL-M 540)

### 1.3 The growth in the demand for aged care services

Australians have added 6 years to their life expectancy at age 65 since the 1980s, and the numbers 65+ will double in the next 20 years. The 100-year lifespan is increasing as a possibility. The community aged care industry is one that is ‘growing-up’ but with a fragmented provider network of around 3000 micro- to large service providers and a lack of a common understanding of the industry purpose, along with inconsistency in vision and beliefs. It has a workforce of almost 360,000 care workers which will increase with an expansion of care in the community and growing numbers of older people.

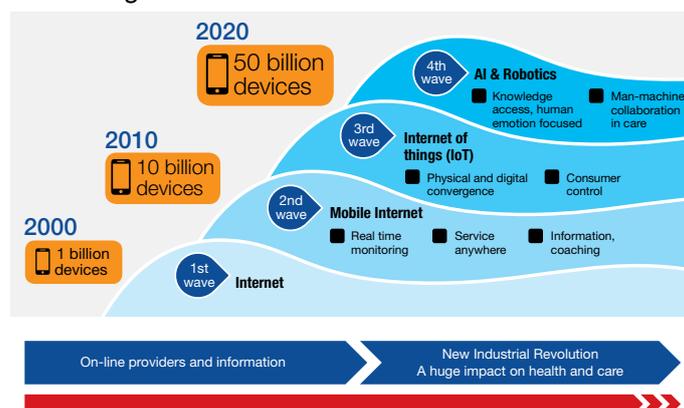
The Productivity Commission Government Services Report, aged care services chapter (Productivity Commission, 2018), highlights the scale of the growing government funding commitments:

- Governments spent \$17.4bn on aged care services, \$4,470 per older Australian, in the last financial year. By comparison, other costs were: disability services \$7.4bn, child protection \$5.2bn, youth justice \$800m;
- Four in five older Australians receive government funded aged care services at some stage before they die, of which the Commonwealth pays the ‘lion’s share’;
- About 70 per cent of public money spent on aged care goes to residential care, the rest on in-home care and other flexible options;
- As at June 2017, more than 200,000 older Australians were in residential care and over 70,000 received in-home care;
- About one-third of older people living in households, and requiring assistance, reported that their needs were not fully met;
- 855,800 people, 3 per cent of the population, are primary carers of older Australians or people with a disability.

### 1.4 The coming reality of disruption

The industry, with its strong base in religious, community group, charitable, and state government organisations provides a large and attractive business opportunity for new players. Already, an Ubercare provider is operating in Adelaide, and similar ones in major capital cities, where care can be ordered online in real time, according to service needs (McCallum & Rees, Consumer Directed Care in Australia: Early stage analysis and future directions, 2017). Figure 2 depicts the impact of devices and types of digital innovations coming into the aged care industry. These devices and applications provide opportunities for opening up the market to new players, new service types and new types of government oversight.

Figure 2: Digital Intersection with Aged Care<sup>2</sup>



<sup>2</sup> Source: McCallum and Rees 2017 with data from Fujitsu for 2000 to 2017

New organisations have signalled that they will come into this emerging industry soon and challenge the existing providers with low cost platforms and a larger scale of operations. There are major issues for the management of this change, such as for organisational cultures that respect consumer preferences, and clarity on industry and provider accountability. While disruption will challenge the industry as it grows rapidly, a key public risk is one of skills shortages and training deficits, which could itself lead to disruptive, panicked responses, independently from the new provider disruption. The aged care workforce is a key issue for the future of this emerging industry.

## 1.5 The High-Touch/High-Tech Quadrant

Theories of high-touch customer service (high-contact customer interaction) during the introduction of high-tech service delivery were developed to describe self-service models in the 1990s and early 2000s (for example, after the introduction of ATMs in the banking industry) (Salomann, Kolbe, & Brenner, 2006). Achieving a balance between high-touch and high-tech was considered a key challenge during the early years of high-tech service delivery, an issue that remains relevant for non-digitally savvy older people (McCallum & Rees, Bridging the Digital Divide, 2017).

**Table 2: The intersection of high touch customer service with technology**

	High-Tech Example: <i>The use of wearable digital devices for complex monitoring of clients to identify risk and transmit tailored information to family.</i>	Low-Tech Example: <i>Having staff routinely monitoring gait, blood pressure and other signals of clients and recording these manually.</i>
High-Touch Example: <i>A restaurant where waiters introduce themselves, talk about the guest's evening, recommend some meals, then offer wine pairings based on their meal choices - or similarly an aged care provider with complex and high-level care planning, communication and involvement with both the client and their family members.</i>	<ul style="list-style-type: none"> <li>• Above average interaction with clients</li> <li>• The use of innovative, new technologies such as digital resources to effectively find, analyse, create, communicate, and use information.</li> </ul>	<ul style="list-style-type: none"> <li>• Above average interaction with clients</li> <li>• Minimal use of technology and digital assistance</li> </ul>
Low-Touch Example: <i>A fast food drive through where you place your order over a microphone, pull up, swipe your card and get your food – or similarly an aged care provider with low level contact and communication and impersonal online systems.</i>	<ul style="list-style-type: none"> <li>• Interaction is minimal and transactional</li> <li>• Use of technology such as digital resources to effectively find, analyse, create, communicate, and use information</li> </ul>	<ul style="list-style-type: none"> <li>• Interaction is minimal and transactional</li> <li>• Minimal use of technology and digital assistance</li> </ul>

Disruption is expected in the form of new digital technologies (Table 2), shifting high-touch service models to low-touch and high-tech, potentially saving substantially on labour and physical infrastructure costs.

Ideally the preferred technological disruption would be to take the sector into the high-touch/high-tech quadrant with co-design between consumers and providers, so that the lower administration and labour costs enhance rather than reduce the personal care and engagement between carers and clients. It remains to be seen if this is the direction of change. Financially, the low-touch/high-tech option would be expected to be the most attractive to providers. Given that social contact is important for older people's well-being and survival, it would be prudent to negotiate frameworks with industry so that it retains an emphasis on face-to-face and personal communication. An example of this was emphasised by one care worker:

*Over-the-phone assessment is no good. People are scared to say the wrong thing in case they get refused service, so you get there and their needs are not what they said. For example, they say they have equipment and you get there and they don't, or they say their husband can walk and you get there and he can't.*

An indigenous care worker also observed:

*My clients miss the old rostering and signing the payslips. It made them feel important doing it. Only a couple have laptops. They can go into the 'Keeping Place' and learn how to do it but they feel the changes are all a bit rude.*

We shouldn't necessarily blame the technology for this but the lack of a co-design process when developing and introducing new technologies. Misuse of the most exciting technology with high potential can only lead to higher costs, wastage and more negativity about the aged care service experience.

In the present time of change listening to expressions of both positive and negative views of experiences is the key to a better future. The media will be a central player in this dialectic, and openness to its role will be a given. The consumer voice is wider than the media and needs to be the driver for change. The goal will be incremental moves from the negatives to a more positive future in the emerging aged care services industry.

## 2. DATA AND METHODS

### 2.1 Design

The National Seniors Social Survey (NSSS) (Wave 7) was cross-sectional in design and conducted by National Seniors Research Director, Professor John McCallum using a questionnaire survey of National Seniors members aged 50 and over. The study was approved by the Bellberry Human Research Ethics Committee of South Australia on 31 January 2018, application number 2017-12-981.

### 2.2 Data

#### 2.2.1 Quantitative survey data

Data in this report were collected in Phase 1 of the National Seniors Social Survey (NSSS) (Wave 7), designed by National Seniors Research staff. The survey was conducted from 14 February 2018 to 4 March 2018. The NSSS Phase 1 asked participants about their experiences of aged care services delivered at home via government funded home support and home care programs, as well as their experiences of being informal carers.

Phase 1 of the NSSS was a self-complete instrument, delivered online using the survey instrument, Survey Monkey. It consisted of the following modules:

- **About yourself**  
A range of questions used to obtain information from respondents about their demographic and socio-economic circumstances.
- **Age care experiences**  
This module asked participants whether they receive aged care services or working as formal or informal carers, their experiences with the aged care sector, including whether services could have been different or better.

#### 2.2.2 Interviews

Qualitative interviews of client/care worker dyads were set up between 14 February and 2 March 2018 and conducted between 5 and 19 March 2018. All interviewees signed a 2-page information and consent form before the interview was conducted. Participants were asked to respond to a series of direct, open-ended questions regarding their experiences of delivering or receiving aged care services in the home, under the Commonwealth Home Support Program (CHSP), the Home Care Packages Program or, from informal carers or other formal providers like the Department of Veteran's Affairs. Interviewers noted respondent's answers during the interview process and completed the texts following this.

#### 2.2.3 "Journey" story collection

The data collected in this part of the study was collected by email and post during December 2017 and January 2018. An invitation by email was sent to National Seniors membership via the eNewsletter, Connect. Participants were asked to voluntarily share their stories about their experiences with aged care services by sending an email or postal letter to the research office.

### 2.3 Method

#### 2.3.1 Quantitative survey

A total of 47,280 National Seniors members residing in all states and territories of Australia with an email address were invited to complete the survey. The survey invitation was emailed, and contained a link to the survey instrument.

**Table 3: National Seniors’ members compared with 2016 Census data**

The age breakdown of National Seniors members as of May 2017 compared with the Census data is as follows:

	NSSS Frequency	NSSS %	All NSA members %	Census 2016 %
50-59	596	13.2	18.6	37.4
60-69	1792	39.9	40.0	31.3
70-79	1653	36.8	28.8	19.4
80+	454	10.1	12.6	11.9
Total Answers	4495 <sup>3</sup>			

**In particular for this study, Phase 1 of the NSSS asked the following questions:**

- The kind of experiences participants have had with aged care and support and home, whether as a carer of someone; a care recipient; having a spouse, parent, friend or other relative receiving services in the home; or no experiences of home support and home care at all;
- For informal carers – whether they have the appropriate skills to do the job required, and whether their own health is or was affected;
- Text comment space for informal carers to describe anything relevant to their caregiving role;
- The estimated number of hours they provide/d aged care services to someone in the home;
- How services were paid for, whether by government, privately, unpaid or unknown;
- The name of the government program, whether CHSP, Home Care Packages Program, or unknown;
- A series of agree/disagree/not applicable questions, including whether workers treated the household with respect, whether services met the needs of the client, whether workers explained things, services were well run, things could be done better or differently, and if Consumer Directed Care is helping needs to be met; and
- Text comment space for any relevant home care experiences to be described.

<sup>3</sup> Although N=4,536, only 4,495 gave their age.

### 2.3.2 Interview method

During client/care worker interviews, the following questions guided the interview process:

For the aged care consumer:

1. Do you know the type of funding you receive?
2. Does your care worker treat your household with respect and do you have a good relationship with them?
3. Are your needs met?
4. Do workers know what they're doing?
5. Is the service well run/coordinated?
6. If there are issues with care provision, what category do the issues fall into: caring, cleaning, communication, convenience, administration, fees, other?

For the care worker:

1. What kind of care provider do you work for (e.g. not-for-profit, private)?
2. What attracted you to the industry?
3. Has the job fulfilled your expectations?
4. Will you stay in the industry? Under what conditions?
5. If you know co-workers who have left the industry, why do you think this happened?
6. What can be done to encourage workers to stay in home support/home care?
7. Does the consumer treat you with respect and do you have a good relationship with them?
8. Do you believe your care services meet their needs?
9. Do you feel your training is adequate to cover all the situations you need to deal with in the course of your work (e.g. dementia care, dealing with the socio-emotional needs of the client, the ability to clean professionally)?
10. Do you believe the care provider you work for administers and coordinates the service adequately?
11. If there are issues with care provision, what category do the issues fall into: caring, cleaning, communication, convenience, administration, fees, other?

Clients and care workers were interviewed as dyads (i.e. the provider interviewed provided the care to the client interviewed) unless one party declined at a later point in the process. They were not asked to comment on one another at any point nor did they do so except unprompted in very general ways. This was designed to ensure they were commenting on the same service systems, needs and expectations, and physical locations.

### 2.3.3 Story collection method

Three open-ended questions were asked as a guide to allow for flexibility and give respondents the chance to tell their story in whatever way was relevant to them.

- We would like you to indicate where and how you had your experience with the aged care sector;
- The type of aged care you had the experience with; and
- What your expectations of good services would be.

Eight responses were received, seven from women, and these were analysed to identify themes, as set out below. In some cases, a correspondence between Research Director, Professor John McCallum, and the respondent ensued, in an attempt to capture the consumer's journey from the trigger for care, to informal care provided by family members, home support and home care, and then entry into residential care. Since there was consistency in the issues being raised by respondents we chose not to extend the project to gain more responses. It should be noted that these 'journey stories' were submitted freely by people who had a story they wanted to make public. They are predominantly negative and, although not exclusively, about journeys where the end point is residential care.

## 2.4 Analysis

A total of 4,536 surveys were completed for the NSSS, a response rate of 9.6 per cent. The software package Stata was used to analyse the data.

Interview transcripts, journey stories, and text box comments were read to identify themes. Systematic text condensation was conducted for thematic analysis of meaning and content.

## 2.5 Sample

**Table 4: Basic characteristics of the NSSS sample, 2012-2018 (%)**

	2012	2013	2014	2015	2017	2018
<b>Age (unweighted)</b>						
50-64	48.0	42.2	44.7	43.9	33.3	30.6
65-79	40.9	42.8	43.8	43.3	58.3	59.3
80+	11.2	15.0	11.6	12.8	8.4	10.1
<b>Gender (unweighted)</b>						
Female	54.3	55.9	53.3	54.2	56.2	42.9
Male	45.7	44.1	46.7	45.8	43.8	57.0
Other	-	-	-	-	-	0.1
<b>State (unweighted)</b>						
NSW	29.9	28.8	29.5	30.7	21.8	22.1
VIC	25.8	25.8	25.9	24.7	14.9	14.0
QLD	17.1	18.1	17.4	18.7	42.2	42.4
SA	9.6	9.5	9.3	9.3	4.5	4.5
WA	10.3	11.1	10.1	11.2	8.9	8.8
TAS	4.1	4.1	3.5	3.0	2.5	2.3
ACT	2.2	2.0	2.3	2.0	3.7	3.8
NT	1.0	0.6	0.6	0.4	1.5	2.1
<b>Education (weighted)</b>					<b>(unweighted)</b>	
Not completed high school	52.1	50.1	49.0	42.3	32.2	42.5
Completed high school	47.9	49.9	51.0	57.7	67.8	57.5
<b>Other qualification</b>					<b>(unweighted)</b>	
Yes	-	-	-	-	77.5	79.2
No	-	-	-	-	22.5	20.8
<b>Highest level of qualification</b>					<b>(unweighted)</b>	
Certificate	-	-	-	-	24.8	21.3
Diploma	-	-	-	-	26.1	25.0
Bachelor degree	-	-	-	-	26.5	19.5
Post-grad dip/cert	-	-	-	-	-	15.1
Masters/Doctorate	-	-	-	-	13.2	12.4
Other	-	-	-	-	9.4	6.7
<b>Employment</b>	<b>(weighted)</b>				<b>(unweighted)</b>	
Currently in the paid workforce	43.2	41.5	40.3	40.5	27.0	26.3
Not currently in the paid workforce	56.8	58.5	59.7	59.5	73.0	73.7
<b>Country of birth</b>	<b>(weighted)</b>				<b>(unweighted)</b>	
Australia	77.6	80.9	80.8	79.6	75.0	76.6
Other	22.5	19.1	19.2	20.4	25.0	23.4
<b>Marital Status</b>	<b>(weighted)</b>				<b>(unweighted)</b>	
Married/de facto/living with partner	62.3	63.7	63.6	63.5	63.8	62.4
Divorced/separated/never married/ widowed	36.4	35.8	36.4	36.7	33.0	37.6
Other	1.4	0.5	0.0		3.2	-
<b>Total</b>					<b>100%</b>	

### 3. MAPPING THE SERVICE EXPERIENCES

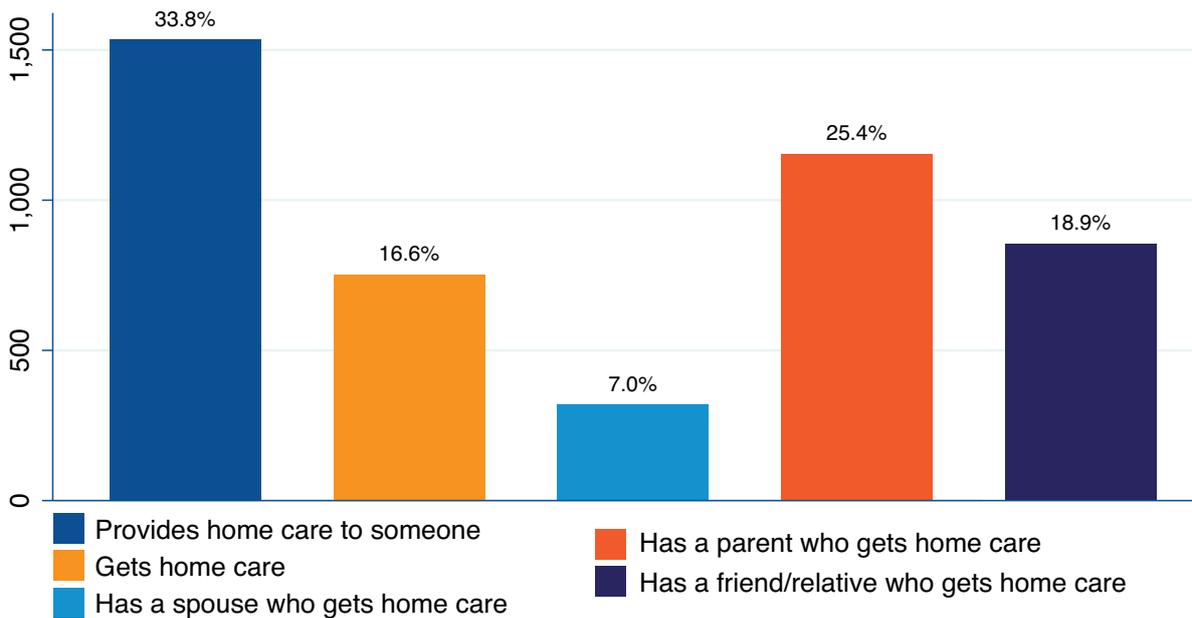
The Legislated Review of Aged Care by David Tune 2017 (Tune, 2017) gives a picture of the current aged care workforce. The aged care sector employs 366,000 workers or 3 per cent of Australia’s workforce. This workforce is largely female and working permanent part-time. Home support and home care workers are referred to as ‘personal care workers’ by Tune, and as ‘the formal workforce’ in the Aged Care Roadmap (Aged Care Sector Committee, 2016). Both call the families, friends, neighbours, carers and volunteers who care for and support elderly people the ‘informal workforce’. Informal carers provide the majority of care for older Australians.

#### 3.1 Type of care experiences

Many people express the wish to stay living at home as they get older, even if they need help with some of their daily tasks. We asked respondents to the survey about any experiences they have had with aged care at home, specifically where someone comes in to help with tasks such as cleaning, cooking, transport or medical treatment. They were asked to comment on any situation that applied to them, now or in the past.

*QUESTION: Please select any situation that applies to you, now or in the past:*

**Figure 3: Experiences of aged care (NSSS Wave 7, 2018; N=4536)**

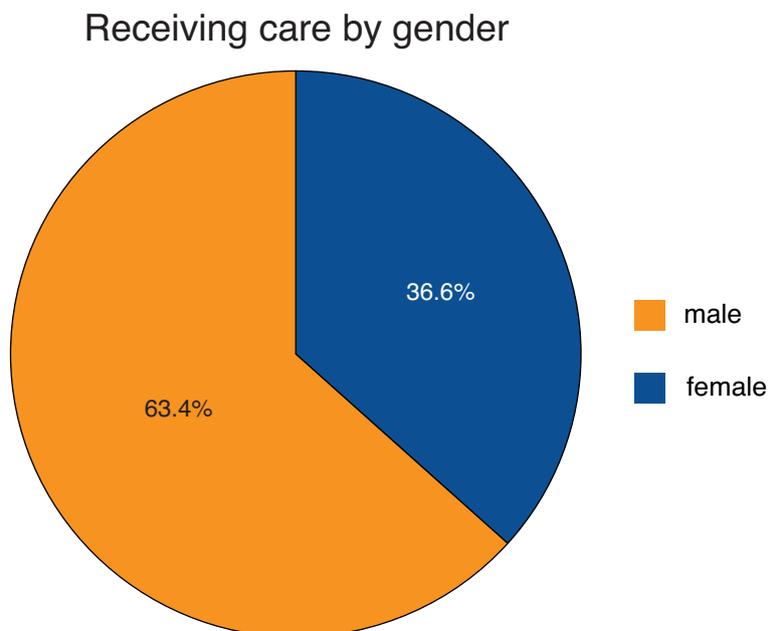


As shown in Figure 3, of the total survey population, some 34 per cent were or had themselves been a carer for someone, 25 per cent had a parent who had help at home with some tasks, 19 per cent had a friend or relative who got help at home and 17 per cent got help at home with some tasks themselves. 33 per cent said they had no experience of this kind. The experiences of care are not only direct but also indirect through family and friends.

## 3.2 Those who are receiving care

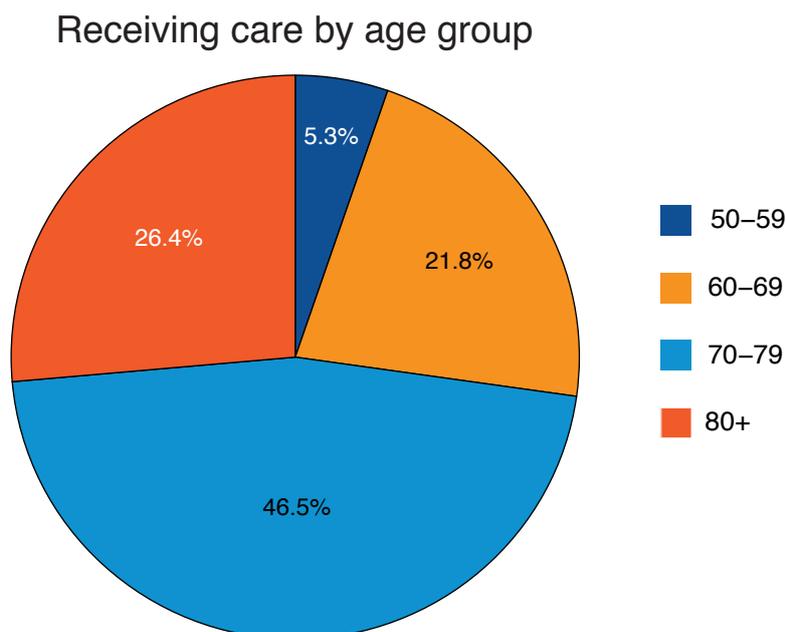
Of participants who said that they were getting care at home themselves, around two-thirds were women and one third were men.

**Figure 4:** *Receiving home care by gender (NSSS Wave 7, 2018, N~ = 750)*



As would be expected, the majority of people receiving home care were aged 70+, as can be seen in Figure 5 below.

**Figure 5:** *Receiving home care by age group (NSSS Wave 7, 2018, N~ = 750)*



It is interesting to consider who is receiving care in terms of the total population of survey respondents.

**Table 5: Statistics on who is receiving care from the population of all respondents (NSSS Wave 7, 2018; N~= 4500)**

<b>Gender</b>	14.3% of men 18.6% of women	p<0.001
<b>Age group</b>	6.7% of those aged 50-59 9.1% of those aged 60-69 21.1% of those aged 70-79 43.6% of those aged 80+	p<0.001
<b>Living with a partner</b>	12.0% of those living with a partner 24.5% of those not living with a partner	p<0.001
<b>Children</b>	16.4% of those who have children 17.5% of those who don't have children	p=0.455
<b>Health</b>	5.3% of those in excellent health 14.2% of those in good health 31.8% of those in fair health 48.9% of those in poor health 66.7% of those in very poor health	p<0.001
<b>Savings value</b>	26.3% of those with savings value <50K 20.3% of those with savings value 50-100K 17.8% of those with savings value 100-200K 20.6% of those with savings value 200-300K 15.0% of those with savings value 300-500K 12.6% of those with savings value 500-750K 10.5% of those with savings value 750K-1.5M 11.8% of those with savings value >1.5M 26.5% of those who don't know savings value 15.7% of those who would rather not say savings value	p<0.001

The profile of people receiving care followed the expected pattern being higher for women, older age, worse health and lower savings levels. It is notable, however, that there was no significant difference between those who had or didn't have children (Table 5).

### 3.3 Those with no experience of aged care at home

To plan for future care needs, it is important to also consider and compare those of the total population who have not had any experience of aged care at home.

Table 6: Statistics on who has no experience of home care from the population of all respondents (NSSS Wave 7, 2018; N~= 4500)

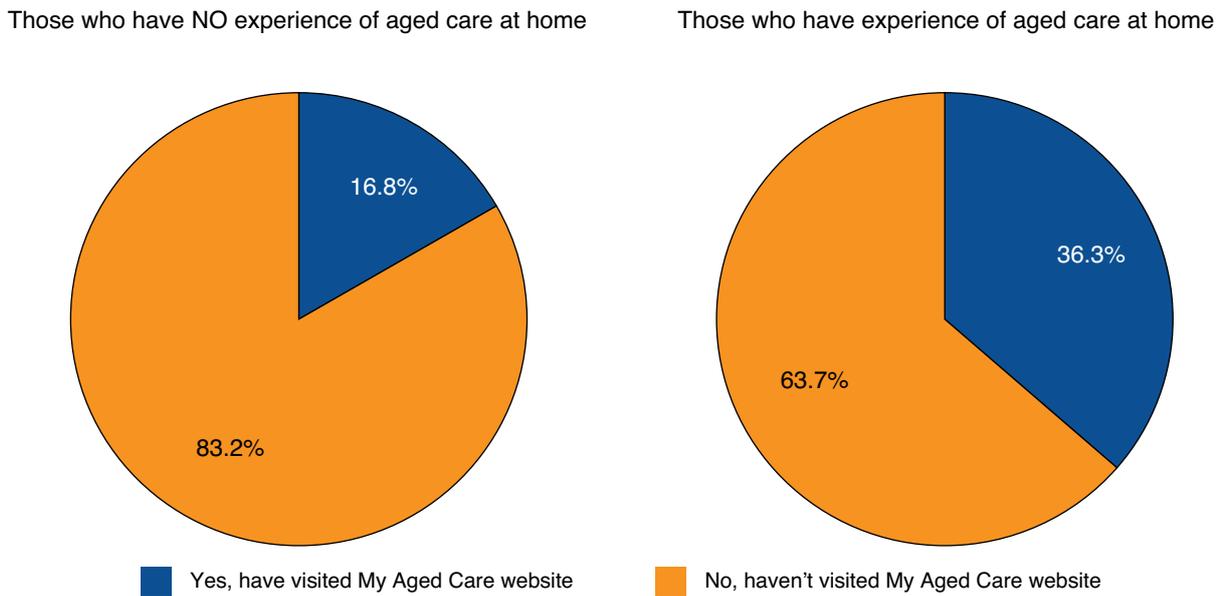
<b>Overall</b>	32.7% of participants have no experience	
<b>Gender</b>	39.9% of men 27.4% of women	p<0.001
<b>Age group</b>	29.9% of those aged 50-59 31.9% of those aged 60-69 37.2% of those aged 70-79 24.5% of those aged 80+	p<0.001
<b>Living with a partner</b>	34.1% of those living with a partner 30.7% of those not living with a partner	p=0.017
<b>Children</b>	33.2% of those who have children 31.1% of those who don't have children	p=0.248
<b>Health</b>	38.1% of those in excellent health 34.9% of those in good health 27.4% of those in fair health 22.2% of those in poor health 12.5% of those in very poor health	p<0.001
<b>Savings value</b>	32.8% of those with savings value <50K 31.1% of those with savings value 50-100K 34.2% of those with savings value 100-200K 34.5% of those with savings value 200-300K 35.2% of those with savings value 300-500K 30.9% of those with savings value 500-750K 35.5% of those with savings value 750K-1.5M 38.0% of those with savings value >1.5M 30.6% of those who don't know savings value 37.6% of those who would rather not say savings value	p=0.288

Having children was not associated with whether someone has experience of aged care at home, nor was a participant's savings value (Table 6).

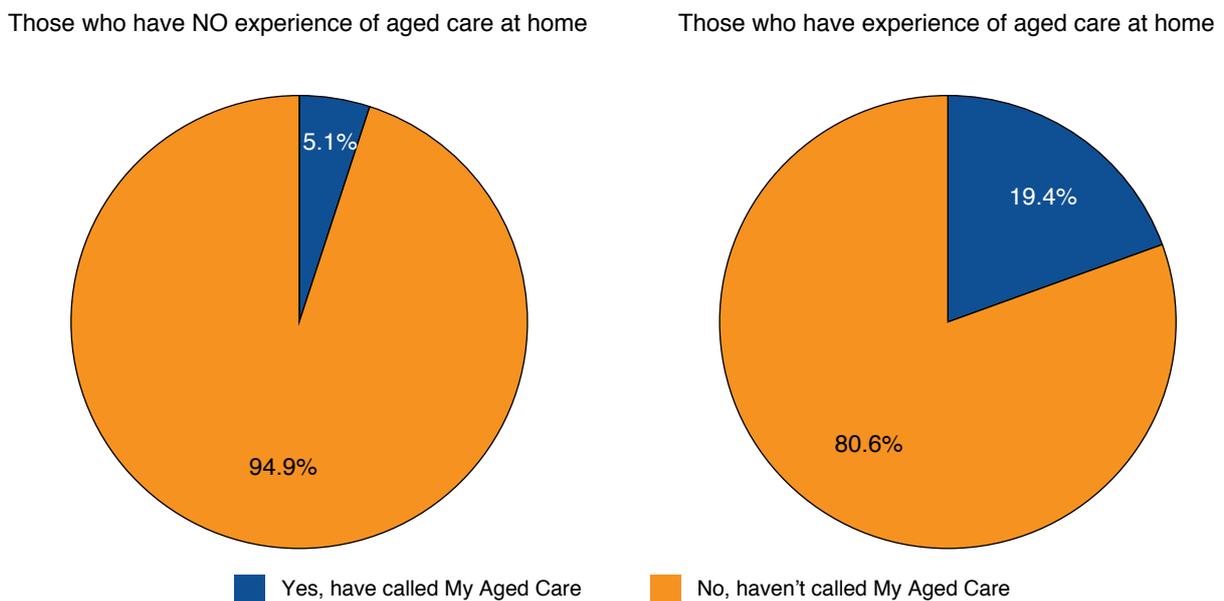
The study sought to find out whether people entering the aged care sector for the first time understand how aged care works and are prepared for future needs. As the following figures show, those with no experiences of aged care have had less visits to the My Aged Care (MAC) website and call centre than those who have, however, the majority of people with some experiences of the aged care sector have also consulted the website

and call centre at lower rates than perhaps expected (Figures 6 and 7). One explanation for this is that some respondents may be discussing what they knew about home support and home care services received by a spouse, relative or friend. As well, people receiving aged care services may have their care arranged for them by their adult children and other family members. The data are suggestive of a lack of interest in future care needs, which means that needs may be being addressed in a time of crisis.

**Figure 6: Knowledge of the aged care sector by visits to the My Aged Care website (NSSS Wave 7, 2018; N~4300)**



**Figure 7: Knowledge of the aged care sector by calls to the My Aged Care call centre (NSSS Wave 7, 2018; N~4300)**



### 3.4 Personal care workers

Personal care workers (the formal workforce) are employed in the areas of home support and home care. The Commonwealth Home Support Program (CHSP) is described as follows:

*The CHSP will help frail, older people (65 years and over, or 50 years and over for Aboriginal and Torres Strait Islander people) who are living in the community to maximise their independence. Through the delivery of timely, high quality entry-level support services which take into account each person's individual goals, preferences and choices - and underpinned by a strong emphasis on restorative approaches, including wellness and reablement - the CHSP will help its clients stay living in their own homes for as long as they can and wish to do so ... The term 'entry-level' refers to support provided at a low intensity on a short-term or ongoing basis, or higher intensity services delivered on a short-term or episodic basis (Australian Government Department of Health, 2016).*

Likewise, the Home Care Package Program is designed to keep people living independently at home:

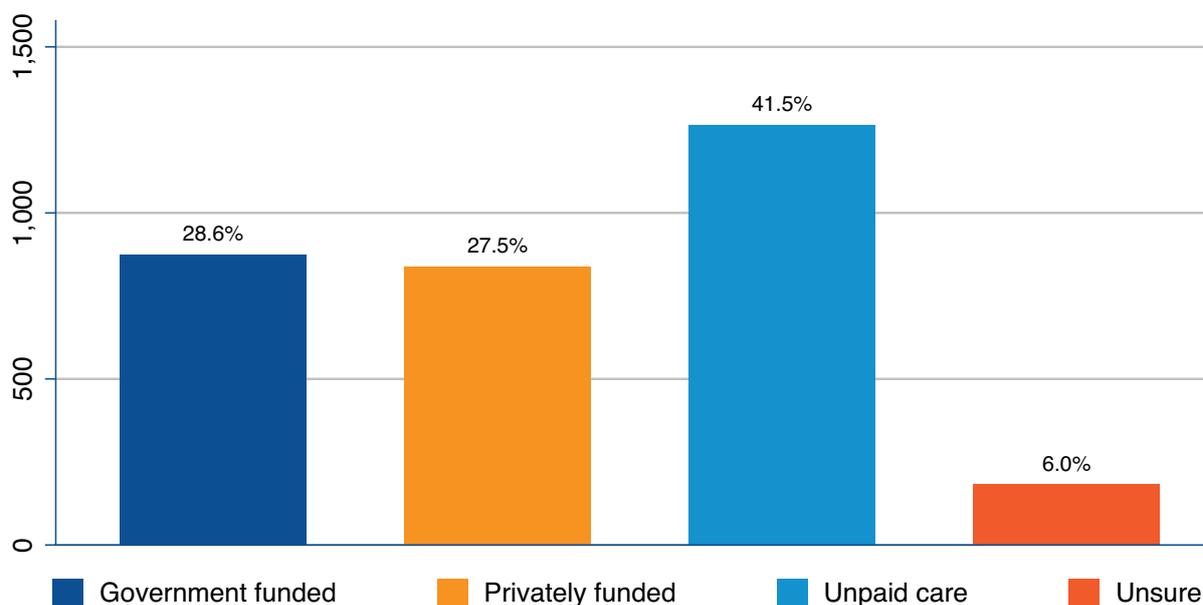
*The Program provides a taxpayer funded subsidy towards a package of care, services and case management to meet your individual needs. There are four levels of home care package. Each level of home care package provides a different subsidy amount. This amount is paid to an approved home care provider that you have selected. The subsidy contributes to the total cost of your service and care delivery. It is also expected that you will contribute to the cost of your care, through a basic daily fee, and in some cases, an income-tested care fee (My Aged Care, 2018).*

Home care packages are delivered under a model of service called Consumer Directed Care, which gives clients more control of services and how they are delivered.

#### 3.4.1 Funding of formal care

QUESTION: How was/is this help paid for?

Figure 8: How formal care is paid for (NSSS Wave 7, 2018: N~=3050)

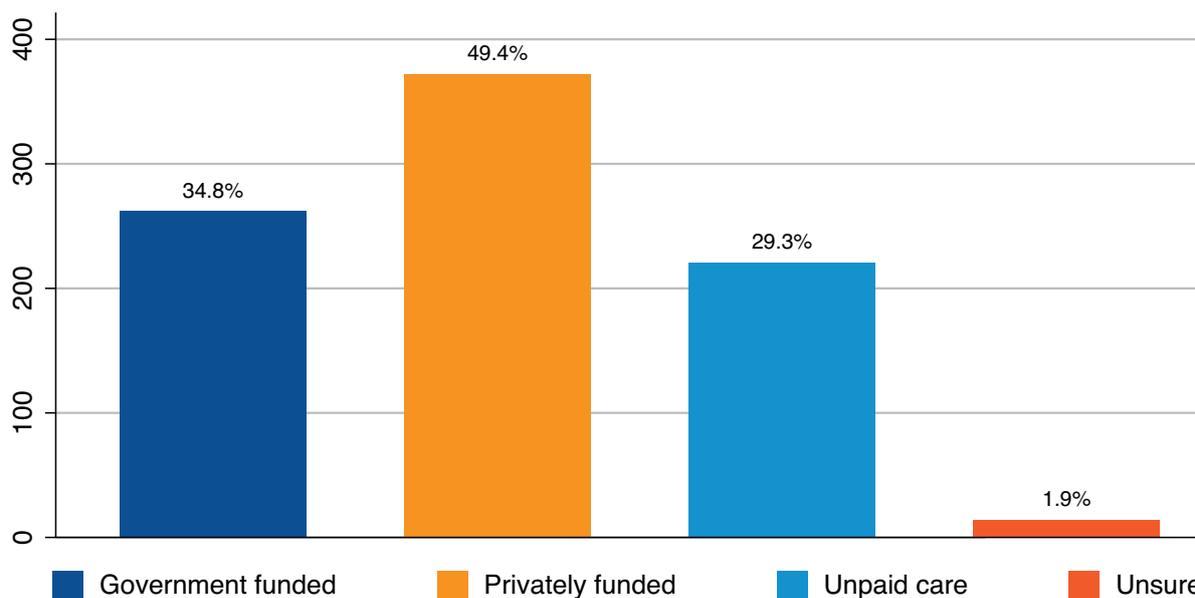


As shown in Figure 8, overall, 29 per cent of respondents indicated that they were funded by a government

program, 28 per cent paid privately for care, 6 per cent were unsure, and 41 per cent of the care was informal, that is, unpaid.

Figure 9 shows that for those who indicated receiving care themselves, 35 per cent were government funded, 49 per cent were paying privately, 29 per cent was unpaid, and 2 per cent were unsure.

**Figure 9: How formal care is paid for – only those who said they were receiving care themselves (NSSS Wave 7, 2018; N~750)**

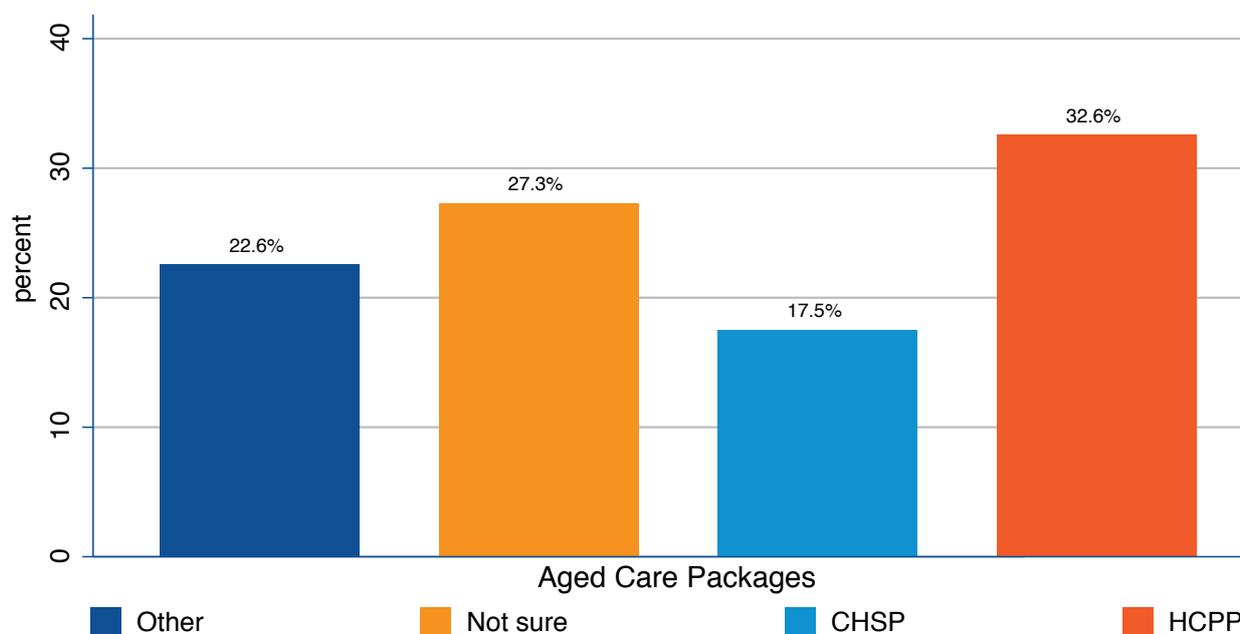


Of those receiving care themselves, four out of five paid privately or received it from an unpaid carer (Figure 9). Those receiving care themselves reported a higher rate of private funding and lower rate of unpaid care than for the larger group which also included people referring to other’s care. We might expect people reporting directly on their own care to have a better idea of whether it is paid or unpaid, although this may not necessarily be the case if offspring organise care for their parents.

### 3.4.2 Government programs

*QUESTION: Do you know the name of the government program that this care comes under?*

**Figure 10: Knowledge of government programs (NSSS Wave 7, 2018; N=4180)**



The government provides home support under the Commonwealth Home Support Program (CHSP), and home care under the Home Care Packages Program. As shown in Figure 10, overall, 27 per cent weren't sure of the program being delivered, 17 per cent received home support, 33 per cent received a home care package, and 23 per cent specified 'other'.

Home Care Packages are dominant but there's a quarter of people who don't know the program of care, possibly because it isn't for themselves.

There were a variety of responses from those who specified 'other' programs, including the following:

- NDIS
- Palliative Care
- Carer pension
- Currently moving from home support to a home care package
- Some listed their provider
- Department of Veterans' Affairs (DVA or DVA Gold Card).

My Aged Care and ACAT were also listed here suggesting, as found elsewhere, that the sector confuses many people.

The Australian Government Department of Veterans' Affairs (DVA) runs the Veterans' Home Care (VHC) Program for eligible Gold Card or White Card holders to assist veterans to continue living at home. Services include domestic assistance, personal care, respite care, and safety-related home and garden maintenance. VHC provides care for up to 1½ hours per week and is not designed to meet complex or high-level care needs. DVA also provides Community Nursing Services to eligible veterans, including assistance with medications and wound care. Veterans with high care level requirements cannot receive care through DVA and must be assessed for home care by an ACAT.

The care experiences that will be explored in the following chapters are therefore from a mix of people who were paying privately for whole or part of their services and/or receiving unpaid care and/or on a government-supported package.

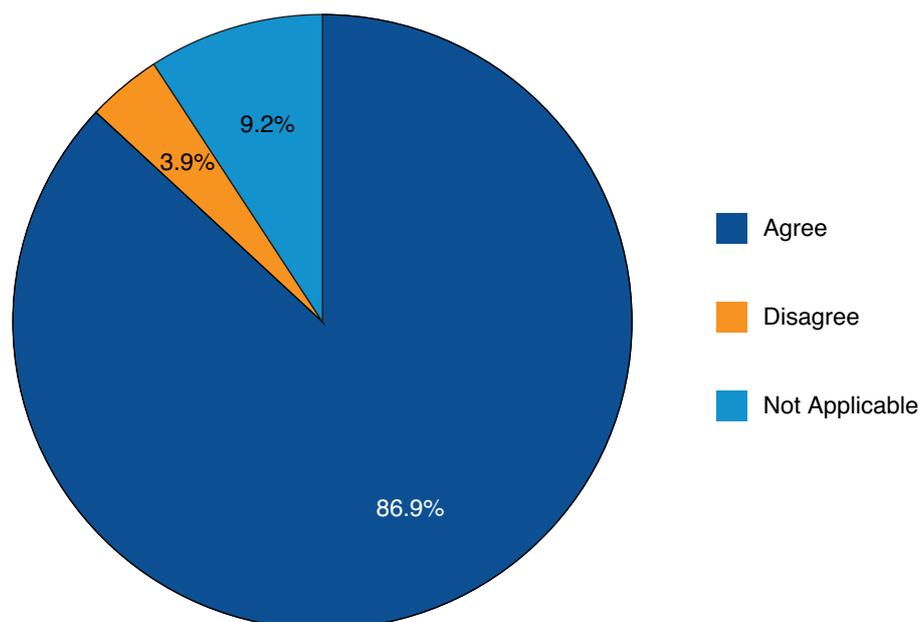
## 4. THE EXPERIENCE OF HOME SUPPORT AND HOME CARE

Participants were asked to agree or disagree with a range of questions about the care being received at home.

### 4.1 Respect

**QUESTION:** *Considering your experiences with aged care at home, would you agree that workers treated the household with respect?*

**Figure 11:** *Workers treated the household with respect (NSSS Wave 7, 2018; N~870)*



As shown in Figure 11, respondents agreed that workers treated their household with respect at a rate of 86.9 per cent. Excluding those who responded with “Not Applicable”, the per cent who agreed to this question was very high at 95.7 per cent. This positive perception was reflected in the comments:

*(1) The helper is always courteous, smiling and respectful.*

*(2) Very helpful and I look forward to their visits every two weeks.*

Some comments, however, did describe a lack of respect, sometimes from the service provider:

*The woman managing my previous service was hopeless, unreliable and rude.*

Staff working for small service providers reflected that the company size or small client load for the care manager was a factor in providing respectful, client-focused care:

*(1) It's about the culture of care – how we as an organisation look after people. The client wants familiarity and to feel valued. We're not large so we can do this.*

*(2) My company is small, boutique. I like that. My bosses know the clients personally. They know who you're talking about when you have problems. Clients are not a number. That's a good thing. Elderly people like to feel they matter.*

Certain themes relating to lack of respect for the household recurred in the data.

#### 4.1.1 Poor attitude to the client

One appalling example of the provider's lack of respect for the clients' needs was expressed by a woman whose husband's needs had recently escalated:

*There was no specific care package available for his needs and I was told by the care provider to push him into the street and provide no further care for him.*

Another provider disregarded the client's specific requests:

*The organisation is unhelpful and offhand. They do not ever tell me when my regular person will not be turning up and they even sent me a person I had previously had and who I asked not to have again.*

#### 4.1.2 Inconvenience

When a care manager was asked about services being delivered at times or in ways that were inconvenient to the client, she indicated that this only happens when provider organisations become too big. In this case, the rostering system will focus on the care worker's schedule rather than on what the client needs:

*Home care is a morning business. Most people need care in the morning, for example, showering and being taken to appointments, or getting washing on the line. But it's about focusing on what the client needs, and asking people what they want. We don't have people waiting all day for a carer to arrive. Elderly people get anxious when people don't turn up.*

Evidence gathered in our survey, however, suggests that the clients' needs are not always respected in this regard:

- (1) *Visits are not set for a pre-arranged time, so I wait around until the cleaner comes. This means I am not able to make appointments or go on outings that day. If the worker arrives in the afternoon, it is too late to hang laundry, especially in winter, and there is no one to bring it inside.*
- (2) *The cleaner comes at various times in the day which means there can be hours of waiting anticipating the cleaner coming. One cannot plan for anything to be done that day as one does not know what time they will arrive. I have asked for an earlier appointment so that Mum is not left wondering and getting anxious, but I'm told everyone wants the morning time slot.*

#### 4.1.3 Lack of continuity of care for dementia patients

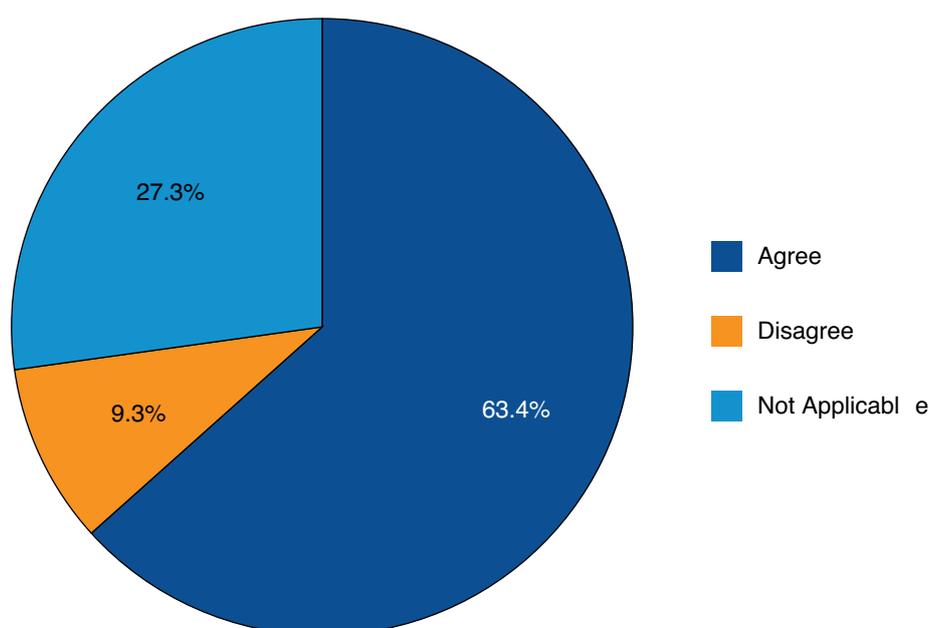
Quite a few respondents shared that their family member's service providers showed a lack of respect for the needs of dementia patients by not sending the same care workers to the home:

- (1) *They kept having to change the people calling on my older sister who was suffering dementia, and this upset her and also made her more aggressive and resistant to having care.*
- (2) *Mum's inability to establish a relationship with just a few care staff made her repeated refusal to accept so many different visiting staff extremely problematic. It made my job even more stressful, as I had to deal with her agitation and distress after each episode.*

## 4.2 Meeting care needs

*QUESTION: Considering your experiences with aged care at home, would you agree that the personal care and support met needs (e.g. clinical care, showering, household services)?*

**Figure 12:** Clients care needs were met (NSSS Wave 7, 2018; N~850)



Overall, 63.4 per cent agreed that their needs were being met in areas such as clinical care, showering, and household services (Figure 12). Excluding the “Not Applicable” responses, the positive response rate to this question was 87.2 per cent. One care recipient, for example, said:

*Yes, so far, I'm getting what I need. I'm not greedy, I'm not wanting more and more. I ask for what I need and have a very good relationship with the coordinator in the office. Whether I'm going to hospital or on holidays, it's very easy to organise anything. It's well-coordinated and well run.*

Issues with needs being met by care services fell into a number of categories.

### 4.2.1 Cleaning

Many respondents complained that Workplace Health and Safety (WHS) constraints on personal care workers meant that the cleaning services did not meet their needs:

- (1) *Some staff won't move furniture, i.e. the chair around the table. They say they are “not allowed to lift”, so imagine a room with dining table and chairs and the crumbs not swept from under the table. This happens in all the rooms they “clean”. Sloppy work half done.*
- (2) *Cleaners were slipshod, scrubbed a clean unused bath, but left used shower uncleaned, do not vacuum under beds or behind doors. Toilet had a high seat over it and this was wiped but the toilet was untouched.*

One respondent checked on an aunt and uncle four times a year from interstate, and said:

*The general cleaning was done but they did not move anything when vacuuming ... when they went into the nursing home, and I had to clean the house, it was full of mice, cockroaches and bugs.*

Many indicated that they decided to employ private cleaners when their need for cleaning services weren't met:

*The WHS rules didn't allow the cleaners to carry a vacuum cleaner upstairs so our upstairs rooms were never cleaned. They changed the bed but weren't allowed to turn the mattress. When we stopped the service, we employed a cleaner privately who hasn't strained her back doing any of these tasks.*

Other elderly people decide to just do the work themselves:

*They were not allowed to do anything above shoulder height, and not allowed to lift anything (even shift a chair to clean under it). As I had to shift stuff as she went from room to room and replace it all, it was almost like doing the job myself ... After several months we scrapped the help.*

Duty of care issues with cleaning were mentioned, as well:

*They did not understand the care that older frail people need. For example, the kitchen and bathroom floors, the toilet seat and vanity, the kitchen counters and sink were all left wet and very slippery, even though we requested they all be dried off.*

In interviews, personal care workers were asked about WHS constraints, suggesting that in some cases it's about the client's expectations being too high, and in others, it's a misinterpretation of the policy by the care worker themselves:

*We can lift chairs. It's common sense. I don't lift more than 20kgs.<sup>4</sup> You have to remember we're not professional cleaners. It's for everyday living. Some clients expect too much, for example, they want the care worker to get up on ladders and clean out the gutters. But some care workers abuse the policy or they've misunderstood what they can do. It comes back to the training.*

While some clients appeared to understand the nature of the cleaning services on offer, calling it "cleaning support", others were confused by the standard of services they were offered:

*One worker said, "we are not professional cleaners", so you are a volunteer? No reply.*

Another care worker said that it depended on the organisation's policy:

*(In one service), we were taught that we don't have to lift the heavy stuff. They were focused more on the safety of the worker. (Where I work now), we are able to lift more than before. We can decide for ourselves and the company is more flexible. They think more about the client, and if the care worker thinks it's okay, they can do things.*

<sup>4</sup> 20 kilos is approximately equivalent to half the weight of a bag of cement.

## 4.2.2 Respite

Not enough access to respite care is an issue for informal caregivers. When asked in an interview if her mother's needs were being met, one woman said:

*Mum receives a lot of services for personal care but not enough respite. She lives with me in a granny flat. I have four kids, one with autism. I need a break, and I need my mind to be at ease when I need to go out. If no one's with Mum, I stress ... I'm mentally and physically suffering from providing the care. It's draining. I put up a wall. I'll break down otherwise. I try to be strong (crying). I want her to be happy.*

## 4.2.3 Issues with assessment or package assignment

Undoubtedly, the client's needs are not met when they wait for too long to be assessed (up to 18 months for one respondent). A clear problem was the need to accept a lower level package until a higher one became available:

*My husband was assessed as Level 4 care, was on Level 2 till recently and is now on Level 3, but it's taking forever for extra funding to come through. He really needs the Level 4. I doubt it will happen though.*

This situation was also described in an interview with a woman whose husband had dementia. She greatly desired to keep him at home:

*My husband was assessed as Level 4 but given Level 2. This is a crime against humanity. We haven't got legislation saying that everyone needs to be attended to at a certain level. Everyone who needs care should get the right money at the right level. I think they're all gouging the system. We went through years of hell because my husband was on Level 2 when he needed Level 4. My son (who has autism) had a mental breakdown ... We need legislation not for minimal standards but acceptable standards.*

## 4.2.4 Regional/remote services

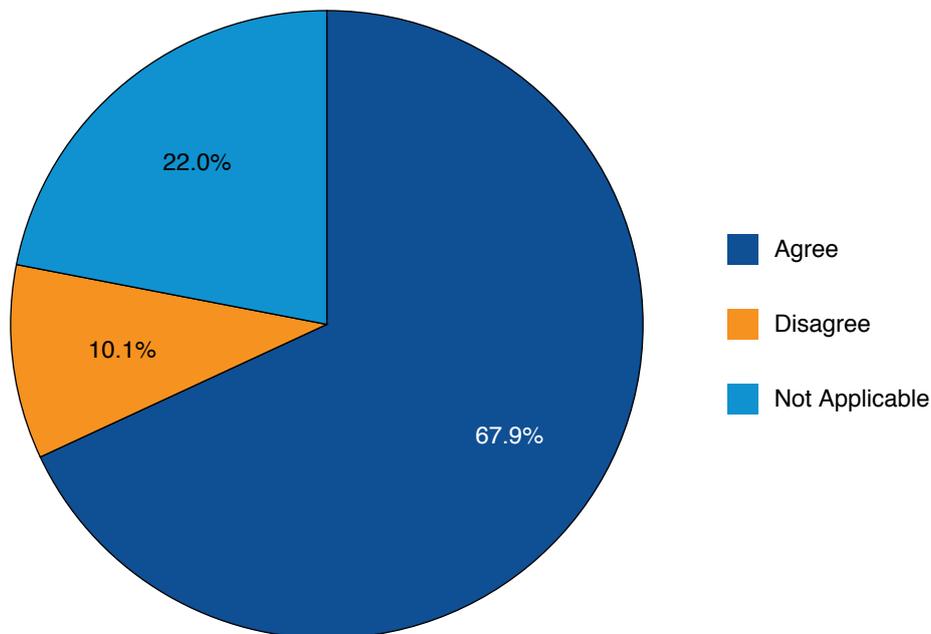
A few respondents from regional and remote areas commented on difficulty of access to the aged care sector leaving them with unmet needs:

- (1) *As I live in a small rural town, the regional centre seems reluctant to visit.*
- (2) *I had great difficulty getting garden maintenance organised with My Aged Care. At first, they said it was only available per head of population which meant rural seniors missed out. I wrote several letters to federal politicians before I received satisfaction.*
- (3) *In rural areas, we do not have other services to choose ... It is false to call it Consumer Directed Care as the consumer doesn't have a choice.*

### 4.3 Communication

*QUESTION: Considering your experiences with aged care at home, would you agree that workers explained things?*

**Figure 13: Workers explained things (NSSS Wave 7, 2018; N~830)**



As shown in Figure 13, 67.9 per cent of respondents indicated that personal care workers explained things to the client. Excluding “Not Applicable” responses, the positive response rate to this question was 87.1 per cent.

#### 4.3.1 Language barriers

Language barriers were mentioned as creating communication difficulties:

*They employed persons who were migrants and had difficulty communicating.*

One service provider mentioned how they addressed this issue:

*We try and target language skills with both service coordinators and care workers in certain branches to meet client needs, however, this is not always possible and we will either deal with family members who speak English or use a translation service. Face-to-face is usually best and they will tend to understand a bit more when we are speaking to them directly and can use body language as well. In the past we have recruited a lot of new immigrants as care workers and put them through English classes!*

#### 4.3.2 Poor communication with the client

There were some issues with the personal care worker not speaking to the client:

- (1) The cleaner/carer was always in a hurry and never spoke to the client. Mum became very stressed so we cancelled the agreement and I went back to cleaning Mum’s retirement village unit.*
- (2) Most personnel are more interested in talking on their mobile phones.*

### 4.3.3 Communication with the client's family

In some instances, better communication with the client's family members was desired:

*There were a few issues, including lack of communication with significant others.*

### 4.3.4 The positives of having company

Some comments referred to the fact that the personal care worker was meeting the socio-emotional needs of the care recipient, who often had no other company:

- (1) *My father is in desperate need of seeing and talking to other older persons with similar interests.*
- (2) *My friend was very lonely and mostly quite despondent. However, she responded well to company and being waited on!*
- (3) *The cleaning was a half-hearted wipe over. The major benefit for Mum was the company of the girl who came to do the cleaning, which Mum looked forward to.*

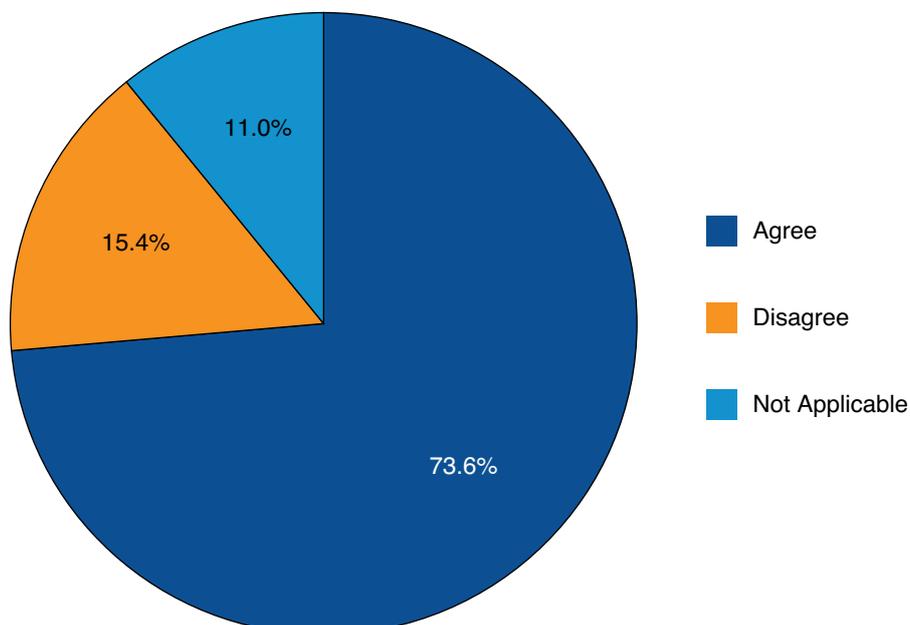
One woman tried to seek care for her mother-in-law who lived interstate and needed socio-emotional support that would enable her to live independently at home for as long as possible. This kind of support was not readily available, and the need for it was not understood:

*Physical support was readily available, e.g. cleaning, showering, assistance with shopping etc. But what she needed was more emotional support, e.g. someone to be with her when she paid bills, dealt with mail, made calls to businesses etc., as she lacked confidence in this area. I got a blank response when looking for such support.*

## 4.4 Training

*QUESTION: Considering your experiences with aged care at home, would you agree that workers know what they're doing and are well trained?*

**Figure 14: Competency and training (NSSS Wave 7, 2018; N~850)**



Almost three-quarters of respondents agreed that workers know what they are doing and are well trained (Figure 14). This positive response rate increases to 82.7 per cent when “Not Applicable” responses are excluded. One personal care worker commented that their organisation encourages ongoing training, high standards, and promotes a positive culture of care:

*The provider I work for are top class in the way staff are vetted and ensuring that staff follow all policies and procedures. They encourage further education in all areas of allied health, and are at the front of age care that is up with the times, teaching our residents and clients modern technology, and encouraging them to be active physically, mentally and socially. Being bold not old.*

Themes relevant to training included the following:

#### 4.4.1 Poor training for dementia care

A personal care worker commented that:

*I had a scary client with dementia that I struggled to handle.*

One man was grateful for the carers who were trained in this area:

*While my spouse was being cared for in the home, I found that some of the carers seemed to have no understanding or training in caring for someone with dementia. For the ones who were obviously well-trained in this area, I was truly grateful.*

Again, the issue of dementia patients reacting negatively to poor care services was raised as an issue:

*We would get complaints that Mum was aggressive – mainly because we would mark on her calendar the days and times that the carers were coming. When they arrived at a different time, Mum would be agitated. It was obvious they had no training in dealing with dementia sufferers.*

#### 4.4.2 Lack of duty of care

A few respondents indicated that duty of care issues occurred in personal care delivery:

- (1) *As a carer by trade, I was most disgusted when my father-in-law came out of the shower freezing because they turned the heaters off as it was too hot for THEM.*
- (2) *My aunt required assistance with showering and ended up in hospital with an infection from them not doing it correctly.*

Another respondent commented on problems with shopping:

*One carer took my mother to do grocery shopping and allowed her to buy Domestos as her washing up liquid, which was a clear lack of duty of care.*

Medication administration was also mentioned:

- (1) *My mother was in her 90s and they were supposed to administer her meds early morning and late afternoon. On some occasions there was only 4 hours between both meds.*
- (2) *A few times vital medication was dropped on the floor that I found.*

One care manager pointed out that their home care workers were not trained medically and were, therefore, not allowed to administer medication.

#### 4.4.3 Theft

Theft was raised by a few respondents:

- (1) *Items were taken from my home and there seems to be no support from police or the organisation to retrieve my things.*
- (2) *There were a few issues with staff taking gifts from the client (valuables such as jewellery, antiques, plants, clothing, crockery) ... If stuff goes missing from the house it can be downplayed because the client had dementia.*

#### 4.4.4 Care worker age

Occasionally, participants commented that the youth of their personal care worker appeared to be problematic:

*Some workers were too young and seemed to be badly trained. Could not get them to commit to a time sometimes.*

A care manager addressed this by saying:

*It's about training and reference checking. I am reluctant to put a young carer in with no experience of Level 4.*

Another personal care worker said:

*The training was great when I first started. You were buddied up with an experienced care worker. I'm worried about the training now. Quality matters to me. I'd like levels of training kept up. I train girls now and they're thrown in the deep end after only one day with an experienced care worker. You need to get to know the clients in this job. It's in the Award that they only get one day with a care worker before working on their own. If I tell my service coordinator that someone needs more training (more than one day), she follows it up. It's better for people to be over 30. Life experience helps.*

#### 4.4.5 Nursing good, cleaning poor

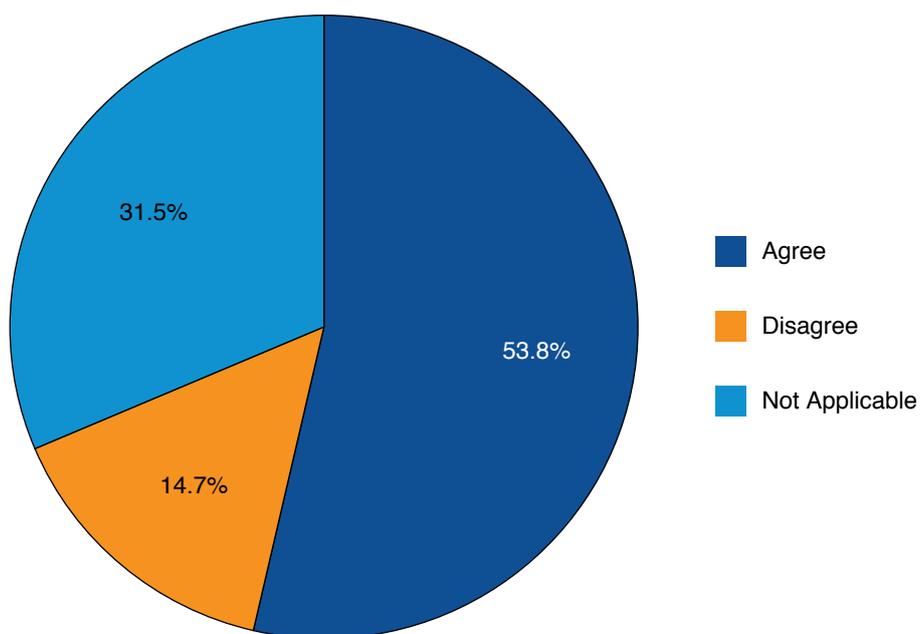
Quite a few participants commented that care workers who looked after their personal needs were good, but cleaners were poorly trained:

- (1) *My mother had a person to look after her personal needs and she was great. The cleaning lady was terrible.*
- (2) *I felt some of the services were slap stick, i.e. cleaning with no real commitment. Nursing services were good.*

## 4.5 Reablement

*QUESTION: Considering your experiences with aged care at home, would you agree that the person receiving care was encouraged to do as much as possible independently, and shown how to do it?*

**Figure 15: Reablement (NSSS Wave 7, 2018; N~840)**



Just over half of respondents agreed that the person receiving care was encouraged to do as much as possible independently, and shown how to do it (Figure 15). Excluding “Not Applicable” responses, 78.5 per cent responded positively to this question. Overall, there weren’t many comments addressing this issue. One participant, however, indicated that her mother’s post-stroke care was less than satisfactory:

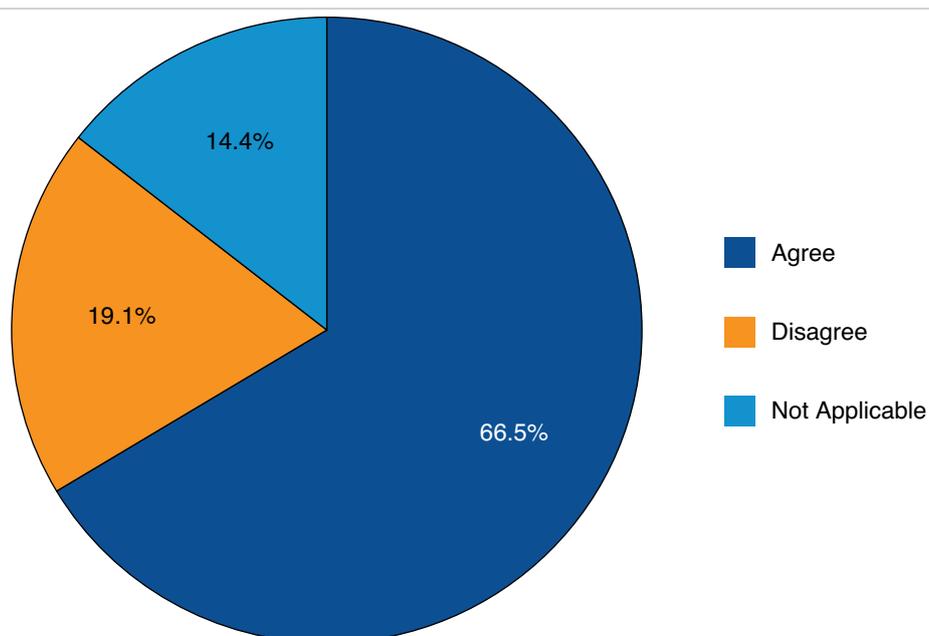
*The service communicated poorly with us, and their understanding of my mother’s complex needs was poor. There was little encouragement for her to do things on her own. Often the worker would just sit and watch TV next to my mother. Although there may have been some minimal companionship benefits in this activity, my mother could have been more actively engaged with a worker to improve her abilities post-stroke.*

An observational study, rather than a survey question, is needed to assess ‘reablement’ because it is a complex concept and task.

## 4.6 Administration

*QUESTION: Considering your experiences with aged care at home, would you agree that the service organisation is well run?*

**Figure 16: Service administration (NSSS Wave 7, 2018; N~840)**



As shown in Figure 16, 66.5 per cent of respondents agreed that the service organisation is well run. This positive response rate increased to 77.6 per cent when “Not Applicable” responses were excluded.

Themes relevant to the administration of the service came under the following categories:

### 4.6.1 Nursing good, administration poor

Many respondents were happy with their personal care worker but said the organisation was poorly run:

- (1) *The workers are very efficient. It is the bureaucracy we can't handle.*
- (2) *Carers who attend are almost exclusively first rate and cannot be faulted. The administration is totally out of touch in their Ivory Tower and have been a total and very distressing nightmare. This was fixed with a change of personnel.*
- (3) *The workers are very good. It is the bureaucracy that is ridiculous.*
- (4) *The carers were wonderful with my father but the management was terrible. I have been in aged care management and I know the quality they should have demonstrated.*
- (5) *The carers who attended generally were caring and helpful. The management was poor, inefficient and caused a lot of grief.*

While we would expect clients to support their providers against their managers, the extent of their comments indicates a need for better quality management.

#### 4.6.2 Poor communication from the provider

Quite a few respondents commented on the poor communication they received from service providers, as the following cross-section reveals:

- (1) *We are very concerned that the administration of these companies does not communicate effectively with the frontline care staff. This has been an ongoing issue for over 4 years.*
- (2) *I do feel in many instances that one hand doesn't know what the other is doing.*
- (3) *There are only problems with the admin side. Assistance times alter and there is no advice. An hour or so difference does not matter but at times there can be up to 4 or 5 hours.*

One care worker pointed out that it was also extremely important for them to have good communication, support, and backup from their administration:

*You need a backup system in the office. Your service co (service coordinator/care manager) needs to get to know the client. We have a new system of the service coordinators going out to meet the client and this is much better. Over-the-phone assessment is no good ...*

*The thing that encourages workers to stay in the industry is good support in the office. You need them to answer the phone straight away and answer emails. It's teamwork. You need all to work together to serve the clients. Having a great coordinator makes a big difference. Having new workers in the office makes life very difficult ...*

*I know sometimes the clients call the office and no one gets back to them. That's annoying to deal with.*

#### 4.6.3 Too much paperwork

While not being something the service provider can change, the burden of the paperwork was expressed in comments as an administration issue:

- (1) *The paperwork and administration is horrific.*
- (2) *I have to deal with 6 or more agencies. I am over filling in forms.*

#### 4.6.4 Administration costs

When asked whether clients asked many questions about the service, one care worker said it was always about fees and their budget:

*Fees come up a lot. They get a budget, e.g. Level 3, but they're only getting 3 hours of care a week. So, they build up a surplus of funds. A lot don't understand the surplus. I'm only beginning to understand that. There are not as many clients with a large surplus now. People didn't understand it at first. The surplus can be used for podiatry, haircuts, a new washing machine. Many get physio once a fortnight. There is less confusion now. They get a list telling them what it can be used for – home modifications, equipment, anything that helps keep them living at home as long as possible.*

Clients either believe that costs could be lowered with better administration or cannot understand that the amount being charged is warranted:

- (1) *Expensive processing/operating costs which could be halved with a little imagination and good management, making our dollar (and the government's) go much farther.*
- (2) *Monthly admin and advisory fees taken from my home care package cut too heavily into funds for services intended for me. My statement for January shows that, in one month, the service provider took out THREE LOTS of admin charges and THREE LOTS of advisory fees, these monthly charges being on top of the hundreds of dollars it took to set up my package in the first place. Also, one worker has told me he got \$10 for one half-hour service whereas my later statement billed that same service at \$31.*

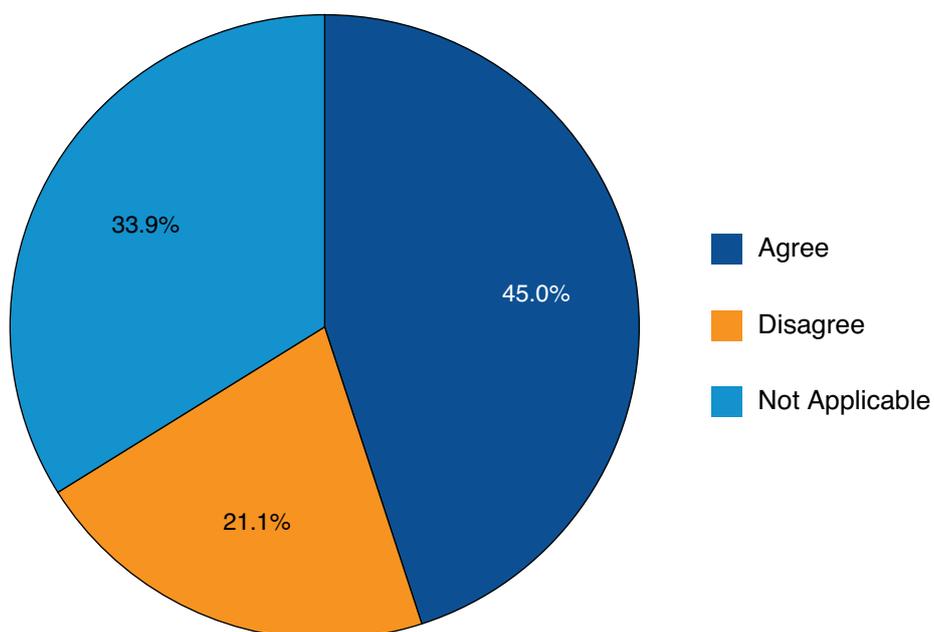
Another respondent indicated that, as a client of a service provider, she had been asked to figure out their accounting system for herself:

*The accounting system is unbelievably poor and they keep asking for money after I cancelled the service. Recently, they asked for money for a service in August last year and I didn't have a service. They are months behind with their accounting and have posted their ledgers to me twice for me to help them with their 'system'. I have spent around seven dedicated hours trying to fathom out their accounting.*

## 4.7 Care coordination

*QUESTION: Considering your experiences with aged care at home, would you agree that care is well-coordinated and connects with other health services (e.g. physiotherapy, podiatry, out-patients)?*

**Figure 17: Care coordination (NSSS Wave 7, 2018; N~840)**



Less than half of the respondents agreed that care is well-coordinated and connects with other health services, for example, physiotherapy, podiatry, out-patients (Figure 17). This positive response rate remained lower than for other questions at 68.0% even with “Not Applicable” responses excluded.

#### 4.7.1 Coordination of care by providers

While this question asked about the coordination of home support and home care with other health services, most text box comments about the coordination of care weren’t referring to cross-sectoral care as such, but to the administration of the service by the service provider, specifically, the “communication problems between the care manager, provider organisation, care workers and us”:

- (1) *I have been promised help that does not ensue. There has been a complete lack of information about services, and poor coordination.*
- (2) *Aged care in general is very uncoordinated and a minefield for carers and relatives.*

#### 4.7.2 Cross-sectoral care coordination

One respondent referred to issues with care coordination when she needed reablement care after a hospital visit:

*Currently waiting for home services that are not sufficiently coordinated. The hospital didn’t set things up properly and I’m at a loss as to who to phone next. I’m not competent so far as searching online.*

In one interview, a man with both parents receiving home care said that cross-sectoral coordination of care services with other health services was extremely complex:

*You get care in place but then there are emergencies. One or the other of my parents has a hospital visit every 6 weeks. You have to stop the home care, deal with the health system, and then get them back into a routine and start the care back up. It’s a challenge to work out the finances, power of attorney, deal with solicitors, the combination of myGov, Centrelink, My Aged Care, and Medicare – it’s a labyrinth from which you feel like you’ll never emerge.*

*Dealing with the health system is the worst. My father broke his hip in the shower while in hospital due to lack of supervision. There’s been a number of those sorts of things. Sometimes the hospital will discharge my parents at night ... Coordination between all the specialists is lacking. The GP is struggling to keep up with it all.*

As mentioned in 4.6.5 Administration Costs, one personal care worker believes Consumer Directed Care now allows providers to coordinate home care with allied health services in a way that’s beneficial for the client and keeps them living independently at home for longer, which is its aim:

*People didn’t understand it at first. The surplus can be used for podiatry, haircuts, a new washing machine. Many get physio once a fortnight. There is less confusion now. They get a list telling them what it can be used for – home modifications, equipment, anything that helps keep them living at home as long as possible.*

The late triggering of care when people are ageing in place, can lead to a sudden escalation in access of the health system, as it did for one man after his wife passed away. The family felt this escalation should have been noticed, and their father's care better coordinated:

*Dad's previous doctor seemed very inactive in addressing the issue of many visits to hospital ... He called for an ambulance late one night and went to hospital, was in for a few hours and then they called him a cab at 4am to send him home alone. No next of kin was contacted ... There is very little to no communication between the various medical facilities, specialists and professionals resulting in missed information and/or appointments being doubled up and having to be re-booked. It also seems that these issues are placing an extra burden on the whole medical system in the area ...*

This woman felt that the lack of integration of medical care for aged people was not only a burden on the health system, but that it would result in her father entering residential care unnecessarily early:

*The likely outcome of these experiences is that he will have to go into residential care, since we can't keep going on this roundabout. This will probably be before it's really needed.*

## 4.8 Overall Assessment of Quality of Home Care

The study has reported seven criteria of good quality care on which people receiving care assessed the quality of their experiences. It could not be clearly assessed from answers why people receiving care chose 'not applicable'. One possibility is that older respondents tend to provide more conservative, measured responses and were reluctant to choose unequivocal responses like 'agree' or 'disagree'. Consequently we have provided the proportional responses, with and without the 'not applicable' category included to indicate the range of the positive sentiments expressed. The items reported were: treated with respect, met needs, good explanations, good training, reablement, well run providers, and good coordination. The consumer directed care question stands separately as a view on its progress but with a high proportion of 'not applicable' responses (57 per cent).

The most supported item, with and without the 'not applicable' category, was that 'workers treated the household with respect' with a 96% agreement when 'not applicable' was excluded. When averaged across all items the agreement rate was 65% (82% with the 'not applicable' removed). With an average agreement rating of 65-82%, these consumer assessments had a strong positive accent even given the expected politeness and tendency to understatement of older people.

Finally 39% agreed that 'things could be done better or differently' and 49.5% when 'not applicable' was excluded. The specific comments in the text indicated where consumers felt there was need for improvement and in specific cases significant changes. In short, there is still much work to be done to improve the positivity of the consumer experience.

## 5. CAREGIVING EXPERIENCES

### 5.1 Formal and informal carers

While the evidence gathered for this study on caregiving is for both formal (paid, government funded) care services, and informal (family, unpaid) care, the experiences of older Australians providing informal care was most prominent in the comments. The role of being a carer is an experience with a degree of risk. The critical question is whether people have the skills, motivation, and support to make this a positive experience.

According to the Legislated Review of Aged Care 2017 (Tune, 2017), the government provided \$1 million per year during 2012-13 and 2013-14 for extra funding to Carers Australia for more carer counselling services. On 1 July 2015, the National Respite for Carers Program was incorporated into the CHSP. Nonetheless, as the data for this study shows, the needs for carer support and respite are still common complaints from informal caregivers.

According to Carers Australia, they provided 20,000 face-to-face, telephone or Skype counselling sessions during 2016-17 (Carers Australia, 2016-17). They provide the following profile of carers on their website (Carers Australia, 2016):

- In 2015 there were 2.7 million unpaid carers in Australia
- Around 856,000 carers (32%) are primary carers, those who provide the most informal assistance to another individual
- The replacement value of the unpaid care provided in 2015 was \$60.3 billion - over \$1 billion per week
- The weekly median income of primary carers aged 15 - 64 was 42% lower than that of non-carers
- More than two thirds of primary carers are female
- The average age of a primary carer is 55
- 272,000 carers are under the age of 25, which equates to around 1 in 10
- Almost all primary carers (96%) care for a family member
- More than half (55%) of primary carers provide care for at least 20 hours per week
- 56% of primary carers aged 15 - 64 participate in the workforce, compared to 80% of non-carers
- It is estimated that carers provided 1.9 billion hours of unpaid care in 2015.

### 5.2 Caregivers and what they do

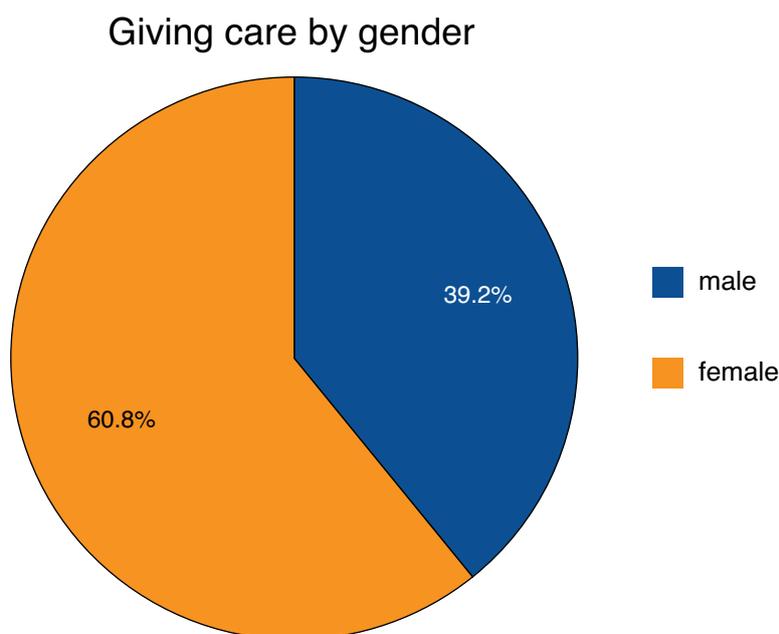
Various types of care were mentioned by caregivers in the NSSS (Wave 7):

- Personal care: bathing, toileting, daily exercise
- Feeding the care recipient, sometimes via a feeding tube
- Taking the care recipient to doctor's and specialist appointments, and pharmacy visits
- Shopping
- Cooking meals
- Cleaning
- Washing clothes
- Home maintenance
- Yard work
- Walking dogs
- Computer support.

### 5.3 Caregiver profile

A third of participants had experience of giving care to someone in the home, whether it be a spouse, parent, friend or relative. Women were more likely than men to be caregivers, and three-quarters of caregivers were between the ages of 60 and 80. Those living with a partner were more likely to be giving care than those who weren't.

**Figure 18:** *Proportion of women and men giving care (NSSS Wave 7, 2018; N~= 1530)*



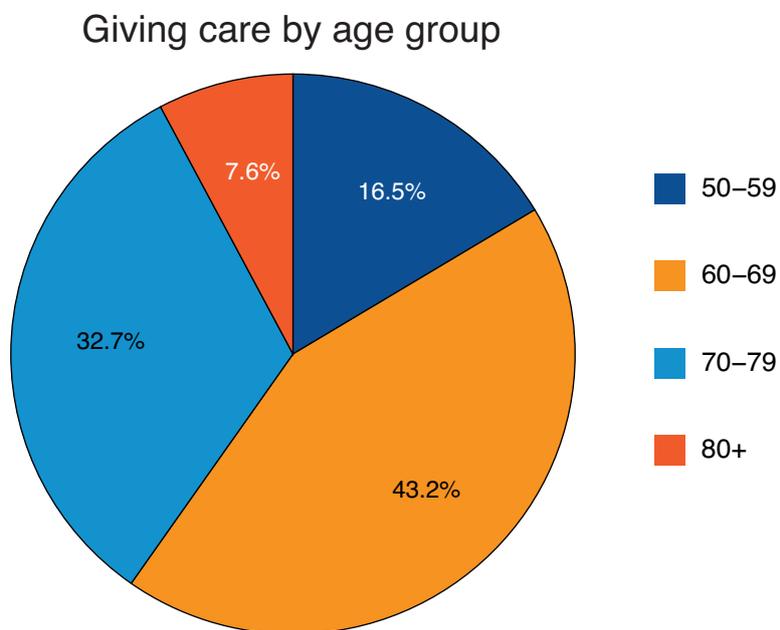
As seen in Figure 18 above, women make up 61 per cent of those participants giving care to someone at home in NSSS (Wave 7). This figure is slightly under the two-thirds proportion of women reported in the Carers Australia carer profile, however the NSSS sample is slightly different in that it is restricted to participants aged over 50 and only takes aged care at home into account.

Looking at those who are giving care in terms of the total population of NSSS respondents, as in Table 7 below, higher proportions were found in lower age groups, which may represent children looking after their parents. Whether respondents were in good health or had children was not associated with whether they were a carer or not, nor was the value of their savings.

**Table 7: Statistics on who is giving care from the population of all respondents (NSSS Wave 7, 2018; N~= 1534)**

<b>Gender</b>	31.1% of men 36.4% of women	p<0.001
<b>Age group</b>	42.5% of those aged 50-59 36.9% of those aged 60-69 30.2% of those aged 70-79 25.8% of those aged 80+	p<0.001
<b>Living with a partner</b>	35.6% of those living with a partner 31.4% of those not living with a partner	p=0.004
<b>Children</b>	33.9% of those who have children 34.7% of those who don't have children	p=0.668
<b>Health</b>	36.4% of those in excellent health 34.8% of those in good health 32.8% of those in fair health 35.6% of those in poor health 12.5% of those in very poor health	p=0.102
<b>Savings value</b>	33.3% of those with savings value <50K 32.7% of those with savings value 50-100K 35.3% of those with savings value 100-200K 32.0% of those with savings value 200-300K 38.5% of those with savings value 300-500K 37.3% of those with savings value 500-750K 35.7% of those with savings value 750K-1.5M 35.4% of those with savings value >1.5M 31.8% of those who don't know savings value 32.4% of those who would rather not say savings value	p=0.437

Figure 19: Proportions giving care by age group (NSSS Wave 7, 2018; N= 1534)



The mean age of carers in NSSS (Wave 7) was 68 years old, higher than the age of 55 reported by Carers Australia in their profile of carers. The higher mean can largely be explained by the restricted age range of the NSSS sample (50 or over), but also by the fact that the Carers Australia figure likely represents all types of care, whereas those identifying as carers in the NSSS were specifically asked if they were helping older people to stay in the home.

## 5.4 Hours of caregiving

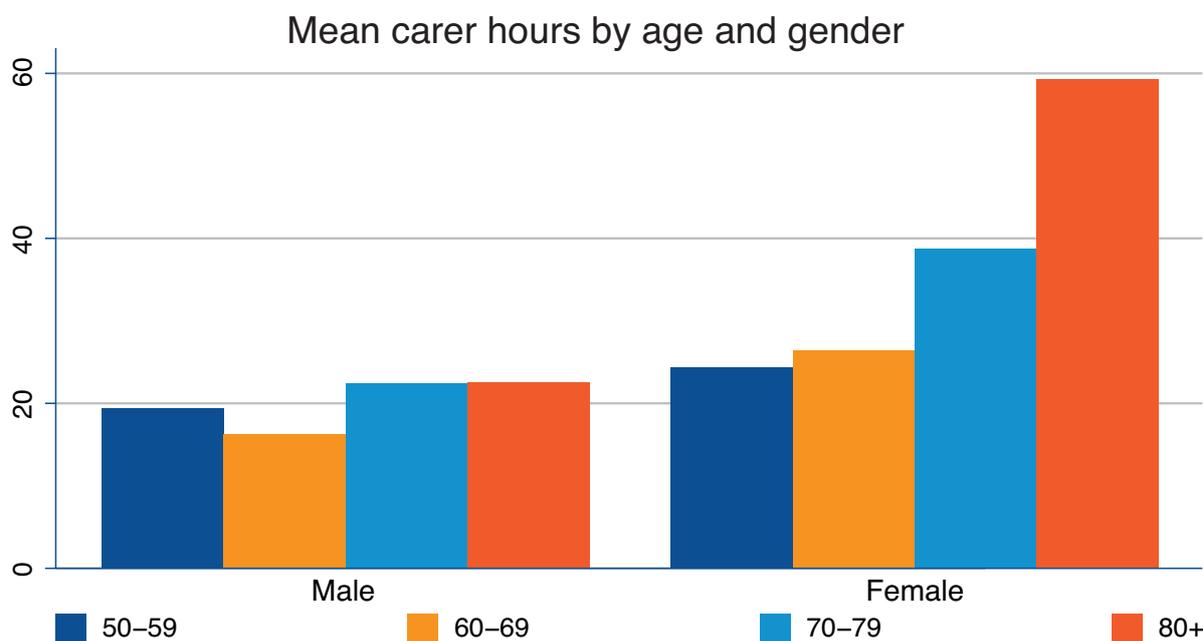
*QUESTION: Please estimate the number of hours per week that you provide/d aged care services to someone at home/in their home.*

**Table 8: Hours of caregiving (NSSS Wave 7, 2018)**

Hours of care per week	Number of respondents	Per cent
0-10	786	55.5%
11-20	248	17.5%
21-40	161	11.4%
40-100	113	8.0%
101+	108	7.6%
TOTAL	1416	100%

Most caregivers reported doing 0-10 hours of care per week, although over 15 per cent of those giving care said that they cared for someone more than 40 hours per week. 78 respondents reported giving care 168 hours a week, that is, night and day (Table 8).

**Figure 20: Mean hours of caregiving per week by age and gender (NSSS Wave 7, 2018; N= 1415)**

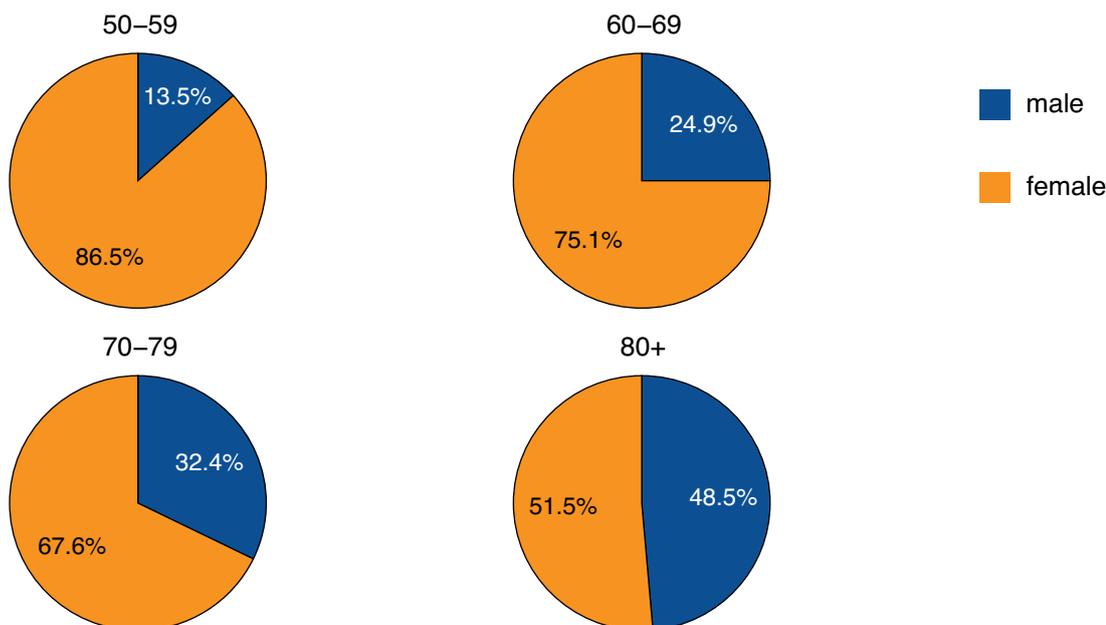


The mean hours of care per week increased for women as age increased, and was highest overall for women in the 80+ age group. While there are less people, overall, in the 80+ age group, those caring for a spouse or partner are often providing full-time care, around the clock (Figure 20). The female burden of caring is evident here.

## 5.5 Effect on health of caregiving

*QUESTION: Considering your experiences of providing care for someone at home/in their home, do you feel your own health is/was being affected?*

**Figure 21:** Identifying as having their health affected by caregiving, by age and gender (NSSS Wave 7, 2018; N~1550)



More than 40 per cent of carers overall stated that their health was being affected by their caring duties. Of those that feel their health is affected, most are women in the younger age groups, but this trend decreases with age so that in the 80+ age group it is fairly evenly proportioned between women and men that feel caregiving is affecting their health (Figure 21).

**Figure 22:** Identifying as having their health affected by caregiving, by gender and age (NSSS Wave 7, 2018; N~1550)

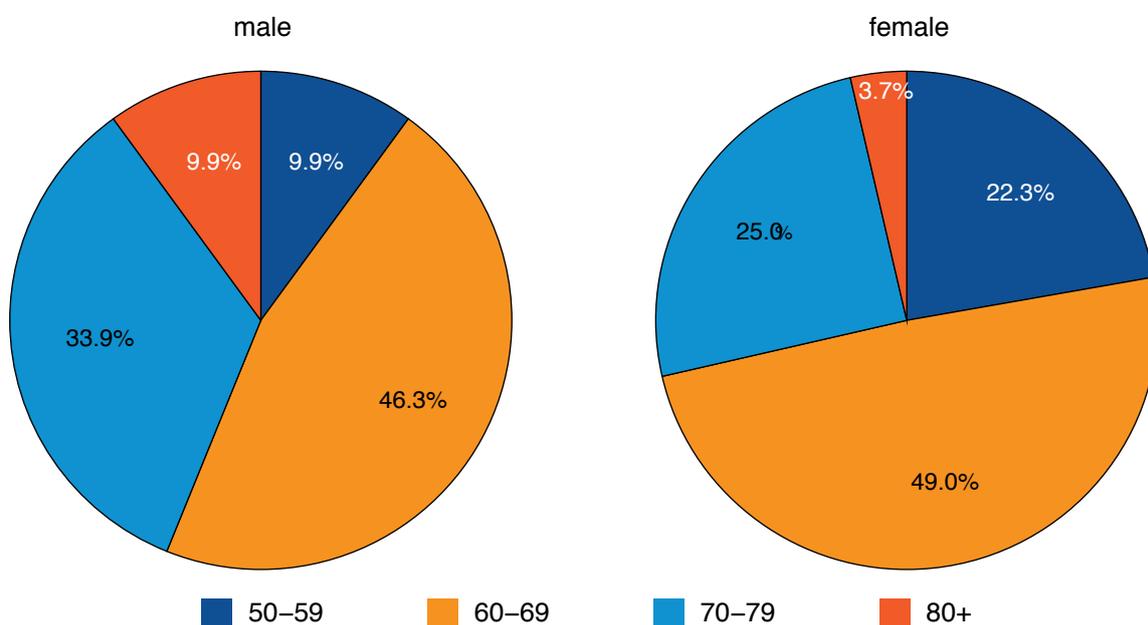
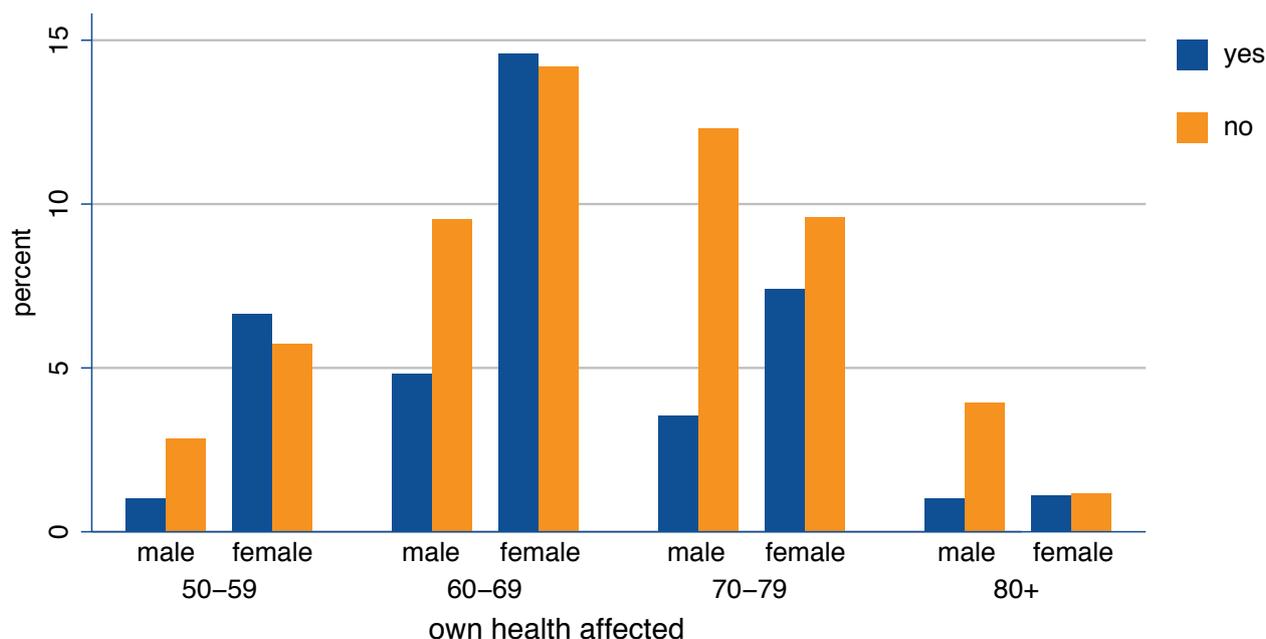


Figure 22 shows that for both women and men, it was those in the 60-69 age group that were most likely to say their health was affected.

**Figure 23: Identifying as having their health affected by caregiving, by age and gender (NSSS Wave 7, 2018; N~1550)**



For women in the 60-69 age group, the frequency of those who said their health was affected is very similar to that of those who said their health wasn't affected (Figure 23). Men report less health effects of care giving than women at all ages except 80+.

### 5.5.1 Physical health

The survey comments gathered evidence that the caregiver often experiences physical health issues:

- (1) *I am my husband's carer, but it is affecting my health. I have disabilities which are getting worse. I have significant rheumatic problems plus various other health problems.*
- (2) *I did get a hernia through getting a wheelchair up steps.*
- (3) *It was extremely stressful and drove me into a heart condition. I still suffer from this.*
- (4) *My mother was debilitated after a fall and I looked after her full-time for seven months. This was an extremely stressful time. I was admitted to hospital due to my run down state and mild depression.*

A few personal care workers in the sector also described the physical issues of care provision:

*Whilst working for community health I was continually frustrated by the hours to do my job being reduced while the workload increased. It resulted in a back injury.*

One respondent commented that the care recipient is provided with care and support but this is lacking for family members providing informal care:

*I was the main carer for my parents and it was very stressful trying to keep all the balls in the air to look after them and also bring up 2 children as a sole parent working full-time. I accessed lots of help for my parents, but there was nothing to support me ... the very many years I was stressed and tired have very much affected my health. If only there was support for long term carers, I am sure I would be in a better health situation.*

Another pointed out that the physical effects may not always occur from providing the care itself, but from not having enough time for self-care:

*My own health suffered as I was unable to quarantine sufficient time for exercise, friendships and time with my husband.*

### 5.5.2 Mental and emotional health effects

Stress, mental exhaustion, and the feeling of being overwhelmed are common:

- (1) *Emotionally it was very damaging.*
- (2) *The psychological drain was immense.*
- (3) *It was an emotionally draining experience.*
- (4) *It is the ongoing little things that make me want to scream sometimes, not the bigger issues.*
- (5) *I find it extremely difficult to cope with the mental stress.*
- (6) *It was incredibly stressful, 24 hours a day.*

Some carers say they are only just coping:

- (1) *It left me very stressed and I am sure I wasn't able to show my mother how much she was loved as I was only just getting through each day.*
- (2) *I am a carer for my wife and son and sometimes I tend to get overwhelmed by it all, but I keep on going.*

One respondent, a trained aged care worker, commented on how difficult informal care is by comparison:

*I have worked in Aged Care for many years but this is a very different situation. The emotional involvement is very stressful and draining.*

Informal care of dementia patients is particularly difficult:

- (1) *It is frightening to witness the sudden onset of confusion in a loved one, and not know the cause. I now tell everyone who is looking after an elderly relative what to look out for!*

(2) *If you have to work and provide care for someone at home (a parent) it is mentally very straining. If they suffer from a form of dementia, you're constantly exposed to their mood swings, nothing is easy, you'd like to just walk away, but you feel it is your duty to stick to your guns, so you continue, but your health is affected.*

One respondent described the frustration in helping a friend with cognitive decline who has clear decision-making impairment:

*I am presently trying to help an elderly friend, but have found that no matter what support is available it is ultimately up to him to have the final say. This process has been an extreme waste of time for me and has caused me no end of stress. A better and quicker process has to be accepted, especially if the person in question is obviously suffering from early dementia.*

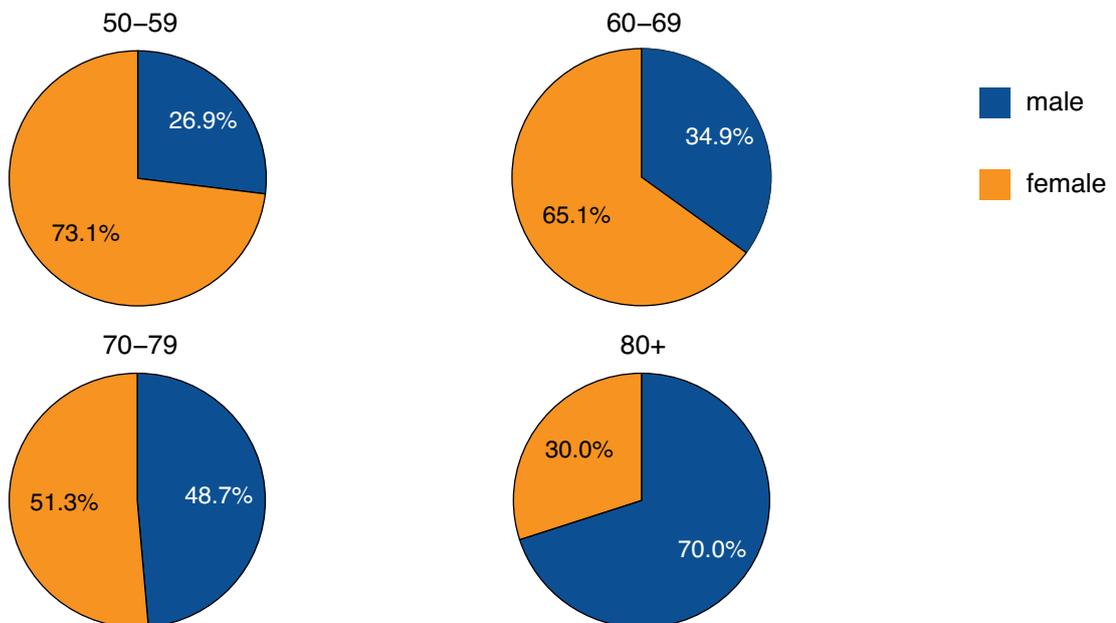
The stress of caring for someone with dementia was sometimes described in extreme terms:

*Caring for a stepmother who had Lewy body dementia. Nightmare. Soul destroying.*

## 5.6 Appropriate skill for caregiving

*QUESTION: Considering your experiences of providing care for someone at home/in their home, do you feel that you have/had the appropriate skills to do the job required of you?*

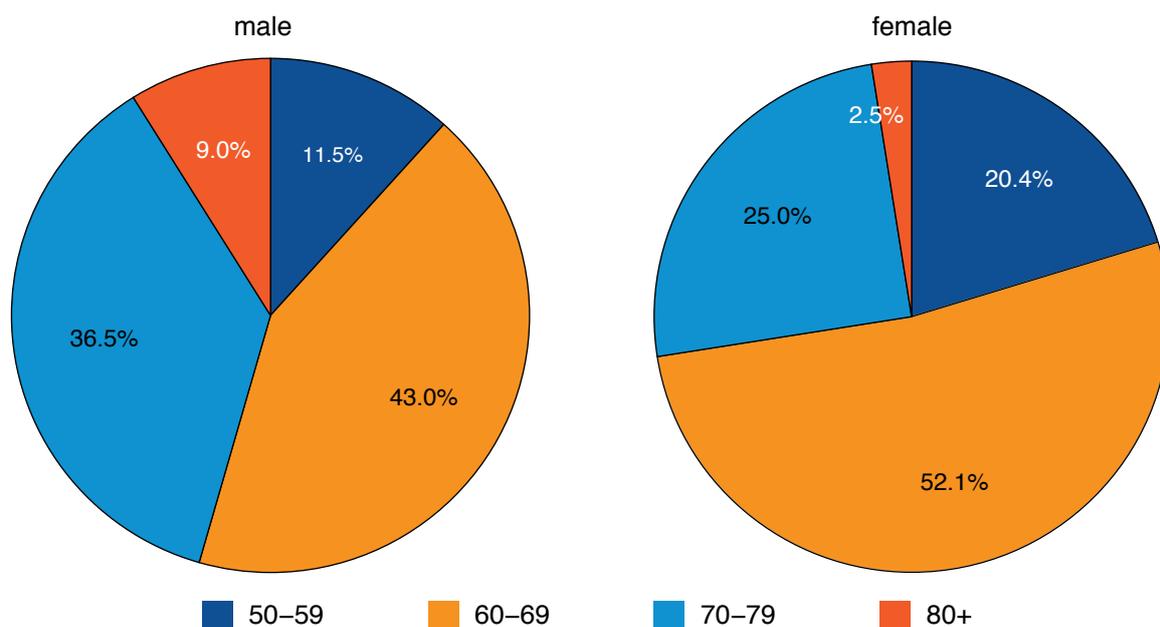
**Figure 24:** Identifying as NOT having the skills appropriate to caregiving, by age and gender (NSSS Wave 7, 2018; N~=1540)



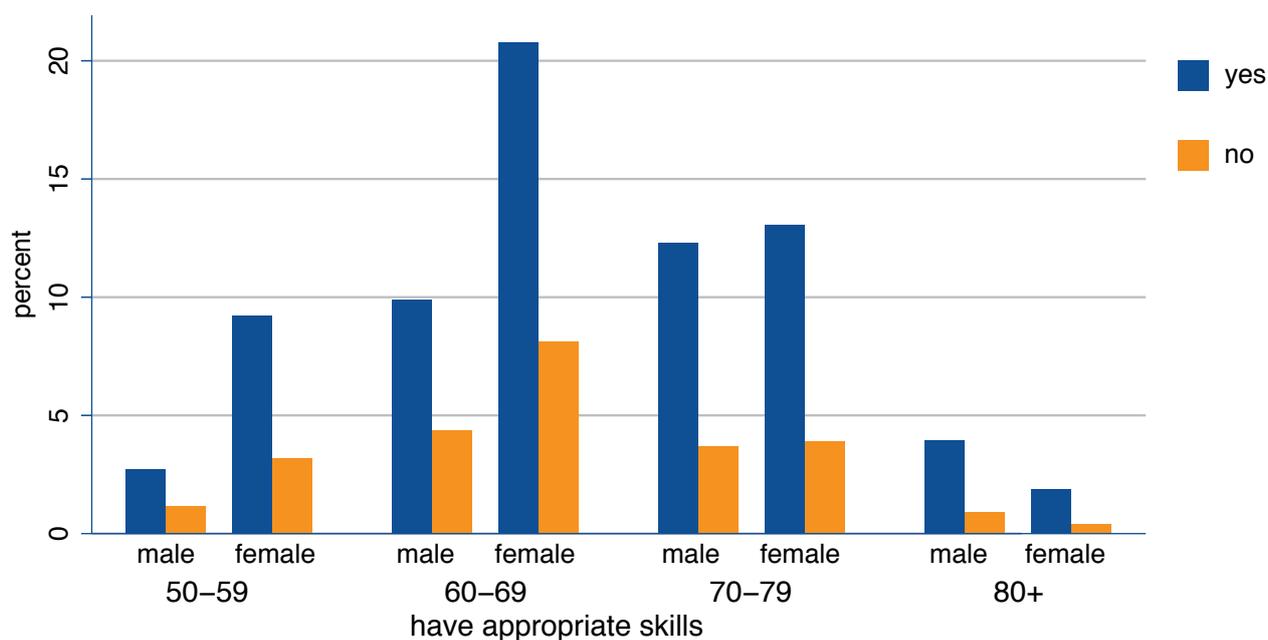
Four out of ten people felt that their health had been affected by providing care but almost three-quarters thought that they had appropriate skills to provide care. There were no significant differences between men and women in their response to this question overall ( $p=0.946$ ). When examining age and gender cross-tabulations of those who don't feel that they have the necessary skills, however, women were more likely to feel lacking in

skills in the younger age groups and men more likely in the older age groups, with men making up 70 per cent of those feeling unskilled in the 80+ age group (Figure 24). Visual trends in the pie graphs suggest that men appear to identify as feeling deficient in caring skills later than women, which parallels their exposure to care provision (Figures 24 and 25).

**Figure 25:** Identifying as NOT having the skills appropriate to caregiving, by gender and age (NSSS Wave 7, 2018 N~=1540)



**Figure 26:** Yes or no responses to the question of having the skills appropriate to caregiving (NSSS Wave 7, 2018; N~=1540)



Overall, women in the 60-69 age group were most likely to say they had appropriate skills to give the care they were giving, followed by women in the 70-79 age group and then men in that same age group (Figure 26).

### 5.6.1 Learning through necessity

Many commented that “you learn as you go”:

- (1) *I simply had to learn on the job.*
- (2) *I learned the skills required quickly – thankfully. The home help was a wonderful mind-saving bonus.*
- (3) *I created skills I didn't have – I think they say that necessity is the mother of invention. It is – and you manage to do things you would never have believed yourself to be capable of. I nursed both my mother and my aunt until each of them died.*
- (4) *No one is fully qualified – you just have to get on with whatever presents today (in the moment) as kindly and resourcefully as you can muster.*

### 5.6.2 Inadequate skills

Some considered their skills inadequate:

- (1) *I could do what was needed but did not feel competent.*
- (2) *When my mother broke her foot, I was totally inadequate at trying to bathe her.*

One respondent commented that needing to provide care without adequate training was unfair:

*I did not have the appropriate training to provide some of the care that was expected of me/dumped on me.*

Another described the lack of skills as “traumatic”:

*An operation left my husband paralysed down his left side. I had to wash, shave, dress, toilet, help him eat and move and use a wheelchair, all of which I had no skills or experience. It was traumatic for us both. However, this helped me when it came to helping my parents and friends.*

## 5.7 Other caregiving issues

### 5.7.1 The need for respite

Many informal carers reported tiredness, exhaustion and not enough time to themselves:

- (1) *These days I am feeling totally exhausted and I don't know how to pull back from the help I have been giving. It is like I don't have a life of my own anymore.*
- (2) *I was able to cope at times, but other times I felt I needed support.*

- (3) *I am always tired having to do the cleaning in the home, cooking, shopping, gardening, paying bills, fixing things around the home or arranging for tradesmen, and I have no time for myself.*
- (4) *The most difficult situation to deal with is the mental exhaustion and the feeling that it is never going to end. There is no respite from the exhaustion.*

The need for respite is more apparent for full-time informal caregivers:

- (1) *The most traumatic time of my life involved providing 24/7 support for a spouse with both medical and cognitive (dementia) difficulties. No, I did not have adequate skills but lacking any respite 24/7 was more problematic than the skills lack. Skills could be gained but not the “time out”.*
- (2) *In a personal caring situation where care is 24/7, I find it tiring and stressful at times. Life doesn't prepare you for the pressure that living as a full-time carer brings.*

Some in this situation have to use their hours of respite for chores rather than self-care or time off:

*I work 24/7 caring for a very disabled spouse and do not always get enough sleep. Although my spouse is approved to get a Level 4 package, we have been waiting 12 months but are managing with 10 hours personal care under the CHSP scheme which includes 4 hours respite for me so I can do the weekly shop and other chores.*

Many mentioned the changes to one's lifestyle when providing informal care:

- (1) *The problem was having to do it full-time to the detriment of our own homes and families.*
- (2) *I think my husband felt neglected.*
- (3) *The main effect is on being able to get about, socialise etc.*

### 5.7.2 Loss of income

Some loss of income occurred due to lost work hours:

- (1) *It can mean you have to curtail your own working life.*
- (2) *I would lose a day's pay (I am a casual employee) to provide transport for medical appointments.*

Paying for care for parents also creates financial strain:

- (1) *Caring for someone is a costly exercise.*
- (2) *Financially, it is a strain to assist elderly parents with ongoing care as I age.*

### 5.7.3 Coping with family dynamics

The difficulty of providing informal care to family members is often the family issues that are brought to the fore:

- (1) *Parents become “entitled” and tend to feel like you are the hired help.*
- (2) *I end up being chastised for things they think I don’t do correctly so then I feel reluctant.*
- (3) *Family members often encounter resistance from the aged parent.*
- (4) *It was difficult dealing with a domineering father who only wanted things his way and expected you to do what he said.*
- (5) *The biggest issue for a carer who is related to the care receiver is for the receiver to become unappreciative of that help. The other issue is recognising the need for the care receiver to be allowed to decide when help is or is not required.*

Some sought help and others said help would have been welcomed:

- (1) *I did not know what to expect, so I read up on it and joined a group, which was helpful.*
- (2) *Having access to a psychologist/social worker to inform myself and my siblings of what our elderly mother may have been feeling, wanting and scared about, would have been very useful.*

One respondent commented about the expectations for care:

*Aged parents find it difficult to let strangers help, or into their lives, so I have found the onus is out on their kids, usually daughters.*

Another respondent described the impact of the caregiving role in later life:

*Having parents with you as you get older is a trying time. You have obligations to help as much as possible ... My wife and I looked after our parents for over 25 years in one way or another and suddenly you realise your own life is coming to a close. Age catches you out.*

### 5.7.4 The need for advocacy and advice

Making decisions on behalf of parents can be stressful:

*I have had problems finding information on aged care services available, especially when not living in the same state. I feel stressed making decisions for a parent where my decision would impact on their health and quality of life.*

## 6. CONSUMER DIRECTED CARE

### 6.1 The introduction of Consumer Directed Care

As described in the Aged Care Legislated Review 2017, aged care has been in transition since 2011 (Tune, 2017). This has included the introduction of Consumer Directed Care (CDC), piloted in 2010-11 and introduced to the Home Care Packages Program on 1 July 2015:

*Home care packages are delivered on a Consumer Directed Care (CDC) basis. This means you (and your carer) have more choice and control over what services are delivered and where and when they are delivered (Australian Government, 2016).*

CDC was intended to give clients of home care:

- More say in the care and services they receive, and the ability to choose and change their service provider;
- The right to plan their care with their service provider and choose their level of involvement in managing the care package;
- The ability to understand how their package is funded and how their budget is spent through monthly income and expense statements;
- Ongoing monitoring and formal reviews of whether their package is meeting their needs.

### 6.2 Consumer Directed Care: a maturing, open market dynamic

Leading Age Services Australia (LASA, 2018) has recently reported on the state of play after the first year of CDC:

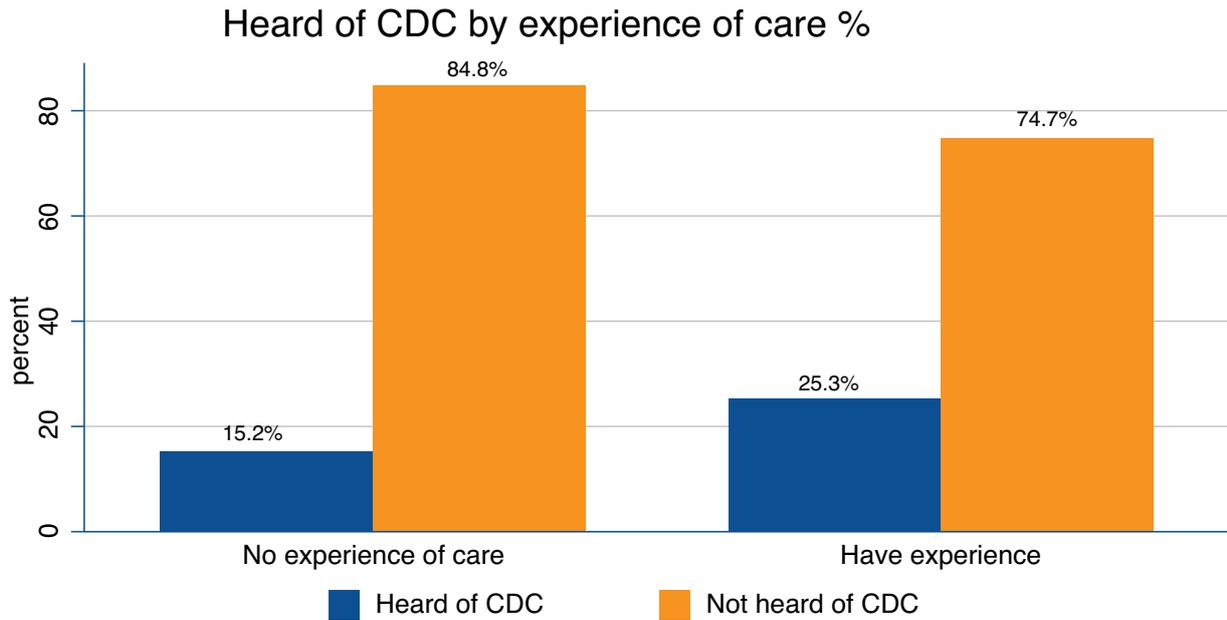
- There was a 23.1 per cent increase in the demand for approval assessments to September 2017;
- The national queue comprised over 100,000 consumers at 30 September 2017;
- Variability in the length of consumer delays to access approval assessments across various regions within Australia;
- Extensive delays for consumers, with many waiting close to twelve months to be assigned a HCP;
- Low rates of HCP activations by consumers across the first six months;
- No incentive for a CHSP consumer to activate an assigned HCP;
- Of those who accessed a HCP, almost 40 percent of consumers have received an interim HCP at a level lower than what they have been assessed as needing;
- There is limited availability for upgrade to a higher level HCP so consumers have unmet care needs, resulting in either premature entry into residential care, the topping up of their HCP with additional Commonwealth Home Support Program (CHSP) services, or the purchasing of additional full fee services;
- A substantial amount of accumulated unspent funds being held by providers administering HCPs for consumers;
- Consumers waiting for a HCP have been diverted to receive interim CHSP support;
- No mandated fee for consumers receiving CHSP support, and inequity in consumer contributions to care that exist across CHSP and HCPs;
- Contentious high and/or widely variable exit fees and administration fees.

In this study, consumers are reporting on their experiences of CDC in a time of system change for the providers of care. While it is very early to be assessing the consumer experience of this new system, LASA reports that most consumers have found the portability of their HCP, the flexibility of services to account for both care needs and preferences, as well as the transparency of HCP funding, a real strength of the home care reforms.

Evidence gathered for this study reveals that awareness of the term Consumer Directed Care is low in both the general over 50 population and people with experiences of the home care sector.

*QUESTION: Have you heard of Consumer Directed Care?*

**Figure 27: Respondents who've heard of Consumer Directed Care (NSSS Wave 8, 2018; N~4250)**

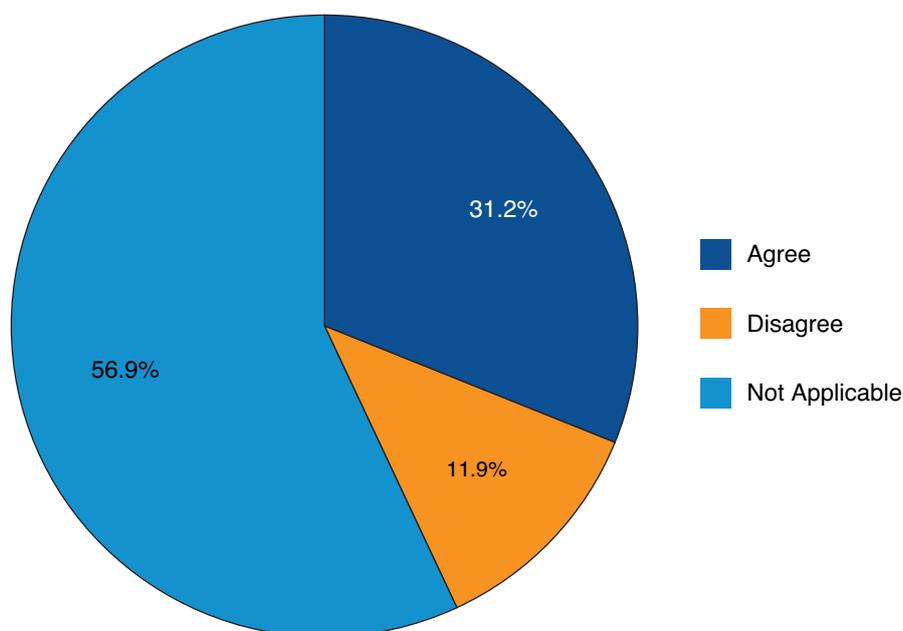


As shown in Figure 27, only 25 per cent of NSSS respondents with experiences of home care services had heard of CDC, and 15 per cent of those who had no experiences of aged care services delivered at home. There may be more who have experienced the increased choice options without being able to name the care system change.

## 6.3 Meeting the needs of the aged care consumer

*QUESTION: Considering your experiences with aged care at home, do you agree that Consumer Directed Care is helping to meet more of my/our needs now?*

**Figure 28: Consumer Directed Care (NSSS Wave 7, 2018; N~4250)**



Despite the general population of survey participants indicating a lack of awareness of Consumer Directed care, 31.2 per cent of respondents who already had experience of aged care at home indicated that Consumer Directed Care is helping to meet their needs more now, with 11.9 per cent indicating that it wasn't (Figure 28). More than half of the respondents who had experienced home care in some way, whether for themselves or via the experiences of spouse's, family members or friends, indicated that this question wasn't applicable to them. There are a few possible explanations for this, including that some respondents were referring to the aged care services delivered to family members and friends and may not have known the answer, and some simply haven't heard the term or don't understand it, as they indicated in the comments. If the "Not Applicable" responses are excluded, 72.4 per cent of respondents did respond positively to whether CDC was helping to meet more of their needs, suggesting that perhaps education and awareness might be the most pressing issues for CDC at this stage.

### 6.3.1 Client perspectives

Some respondents commented on failures in the delivery of Consumer Directed Care. One client detailed the exact price rises he'd experienced, and called CDC a "financial disaster":

*For the 5 years up to the commencement of CDC, there were no financial problems. Suffice to say that now the daily fee is maxed out at \$10.17 per day with an additional daily fee now \$7 making the total daily fee no \$17.17 (or \$240.38 per fortnight). For the 5 years prior to 1/07/2015, the fortnightly fee was \$67.20. So, if you compare that with our current situation for my wife, you will see why I say that the CDC scheme is a financial disaster. Instead of 1¼ hours in the morning, the time had to be reduced to 1 hour to balance the budget. We have had to buy a hoist, bed and mattress as the budget could not accommodate the cost. Total of these three items has been approx. \$12,500.*

Another respondent called CDC a “cop out” and “political correctness gone mad”, saying:

*The care recipient did not have the cognitive capacity to direct herself to the bathroom, much less direct her own care. The service provider took direction from absent and ignorant daughters who never came near their mother for years. They directed that all their mother needed was “fun”. Therefore, the care recipient was taken on outings for coffee/shopping etc. There was no preparation or supervision of proper meals, no laundry. The care recipient was not showered, her body odour was bad, and she was always dressed in dirty clothes.*

*Apart from the initial ACAT assessment for Level 4, daily care needs were not assessed by the care provider. Taxpayers are paying \$millions for this mess. Consumer Directed Care is an excuse for poor care, dreamt up by bleeding heart do-gooders who have no idea of good practice for cognitively impaired people.*

One respondent, as discussed at 5.5.2, also commented that Consumer Directed Care is problematic for clients with cognitive decline, who cannot be expected to be empowered consumers.

By contrast, many viewed Consumer Directed Care positively:

*Consumer Directed Care is a much better system and does meet the needs of the individual.*

More specifically, one interviewee expressed an increased sense of empowerment in the knowledge that she had the right to direct the funds assigned to her as she needed:

*I'm starting to make changes. Now that it's coming from my package, I stick up for myself and have more to say.*

Another client interviewed expressed how much better it was now that the service provider had started sending the care manager out to the client's home to discuss the care plan:

*To maintain communication between the supervisor in the office and clients, the current manager comes to meet the clients. This is the only one I've met in 15 years. It makes a big difference and should be encouraged by management – to know the person, their needs. I admire her for that.*

Consumer experiences are also being affected by an increased sense of competition felt by providers since the introduction of CDC, as one provider commented on:

*There were angry complaints about us stealing clients. In fact, when three clients of a large faith-based group contacted us, we sent them back after helping them with wording on what they wanted. Because they didn't get it again they came back to us ... It's probably due to middle management frustration and performance pressures. With so many changes, larger organisations can be slower to act. Managers are also scared to lose jobs if they lose clients.*

### 6.3.2 Provider/care worker perspectives

Many care workers and managers expressed confidence that Consumer Directed Care was a positive change, giving people more choice. A personal care worker was quoted in 4.6.5 as saying that there was initially a lot of confusion of care package budgets, but as clients begin to understand Consumer Directed Care, they are getting more out of their packages, including allied health services, home modifications, and equipment they need but couldn't afford before.

One provider indicated that the difficulties with CDC implementation remain:

*Consumer directed care progress in the system, and what's needed for progress:*

- *Consumers are finding it challenging to navigate the new systems;*
- *Hard to use their new 'choice & control';*
- *The system is difficult to navigate;*
- *It takes a lot of time and effort;*
- *Difficult to find the appropriate resources and staff to meet their needs and expectations.*

A personal care worker also mentioned in an interview that her care coordinator was now visiting clients at home:

*I think this is good. They see who the client really is. Sitting in the office, the client is just a name. This change was implemented by our service provider.*

Another care worker reiterated the benefits of this practice:

*You need backup in the office. The service coordinator needs to get to know the client. Over-the-phone assessment is no good ... Having a great coordinator makes a big difference. If you have new workers in the office, it makes life difficult.*

A care manager who was interviewed agreed that this role included getting to personally know the clients and work with them on their plan:

*I wouldn't have a carer, physio or cleaner go into someone's home unless I've been in the home myself. I do risk assessment. I think this is mandatory. The care manager should not be a dictator to the family but listen to them and work with them. You can't be opinionated. It's not about you.*

One service provider described the way CDC brought about a change of focus for the organisation:

*This client-directed process has required internal education from the top down, including the Board. They are fiscally responsible, but the key decision determining outcome is higher client satisfaction and added value, not profit. Management has had to help the Board rethink this outcome measure. Higher client satisfaction is a more valuable indicator than dollar value.*

*This culture is carried by the middle management, but most important, they had to train the families to know what the current and new rules were. The client satisfaction focus had to be carried by cleaners, phone answerers, and everyone through the organisation. This took 6 months training and education in large and small groups.*

Care workers also believe that the Australian system is improving and is better than elsewhere in the world:

*(1) I wouldn't go back and work in home care in Japan. The conditions are harder, long hours and less pay. It's better here. I think Australia is good with home care. The clients receive more care than in Japan. We are doing okay here.*

*(2) I have a South African friend who desperately wants to bring her parents to Australia for home care. We have a good system here and the government is doing the right thing. People don't realise what's happening elsewhere in the world.*

Consumer Directed Care is not a 'magic bullet'; it depends on well-trained and open-minded service providers, availability of services, and correct interpretation of people's preferences.

### 6.3.3 Consumer Directed Care challenges

Now, more than ever, an understanding of the influences and the skills requirements of the sector is needed, as home-based care continues to move into the client-directed care era. This shift arose from new ideas about how aged services should operate, which has triggered a seismic shift in the sector for providers that is now being felt by the consumer as well. The future demand for better skills in Consumer Directed Care is currently receiving attention. As one provider indicated, this change requires a consumer-centred, creative, problem-solving culture rather than specific training alone:

*The release of power to client is too hard unless you're well-trained and prepared to use every aspect of your creativity. You have to 'tick their boxes', talk and listen.*

Further, it requires a focus on broader function rather than specific physical limits or targets. This is also central to the practice of reablement which includes working together with the client to maximise their recovery and/or ability to live with declines in function on a daily basis:

*Functional activities of daily living must be the focus not fixed rules or standards. The task is not simply to fix a broken toe but to enable someone to get out of a chair. Improving performance of the complex task of daily living requires functional education. An arthritic shoulder doesn't necessarily require a fixed centimetre washing line height but something at shoulder level. We train staff to work with the function that people have left, maximising potential to the level they can do, not to use set ones. Look at the entire person.*

Consumer Directed Care must be personal and provide services related to the client:

*A client with a long history with music should mean that managers get them to concert programs, and drop the plan for that week.*

Finally, the provider needs to avoid conflicts of interest evidenced in attempting to capture the package money allocated but, rather, provide advice on the best services available for the needs and interests of the client. If these elements are incorporated into training and management then Consumer Directed Care training is actually just good care training.

### 6.3.4 Ambivalence to CDC remains

Some home care recipients expressed very positive views related to their care:

- (1) *The administration has been excellent. They keep in touch by email and try to get the best financial arrangement for us. It's not a money-making exercise for them. I have no complaints. I feel very lucky.*
- (2) *We have a great case manager and assistants who are always willing to discuss any upcoming problems and help solve them as they approach.*

This study, however, has found that many home care clients have not yet been empowered by the introduction of CDC. Some indicated that their needs are not being met in various ways, and some respondents remain confused about the industry, the funding program they're on, the fees they're paying, and some feel that their care is not well coordinated by their service provider:

- (1) *We are told what we can have regardless of differing needs.*
- (2) *When the government changes the system, it takes providers a long time to understand themselves before we know where we stand.*
- (3) *We had up to five carers turns up some days, asking what they were supposed to be helping with. They were all very pleasant and helpful, but we felt the "system" was rather disorganised at that time. We were never told total amounts of the value of our "caring package" or what we could request, at that time. Hopefully things will soon improve. We were as confused as the carers at times.*
- (4) *Consumer Directed Care sounds good, but it only helps if there are resources to direct it ok. I also feel that the cost went up when using other services as there was a loading applied.*

Care workers and managers were, however, confident that Consumer Directed Care is working and had made a positive change in home care:

- I'm proud of what Australia is doing with My Aged Care, the government assigning packages, it's giving people choice.*

## 7. SKILL GAPS AND OPPORTUNITIES<sup>5</sup>

The consumer experiences reported here derive from interactions with a variety of workers providing a wide range of services to home-based aged people, including professional services such as physiotherapy, occupational therapy and registered nursing, amongst many others. Those who provide hands-on basic services, such as assistance with bathing, household tasks, and others, are variously referred to as ‘personal care assistants’ (ABS, 2016), aged care support workers (Seek, 2018), or home care workers (Seek, 2018), and as Community Care Workers (CCW) in the Aged Care Workforce survey, 2012 (Australian Government Department of Health, 2015) and by My Aged Care (Australian Government, 2015). As mentioned previously, David Tune refers to formal workers in this sector as personal care workers (Tune, 2017). In addition, aged care/ support organisations employ management and administrative staff.

Informal carers (relatives, friends and volunteers) provide the most prevalent care encounters to elderly people with their existing skills, occasionally supplemented by some training which they have sought out themselves, or expertise they have gained in prior employment in relevant occupations. The consumer views expressed in this research indicate the centrality of good service provider skills in a high-quality consumer experience.

### 7.1 The community care workforce

As the focus of this chapter is on skills, the size and characteristics of the workforce are the starting point for the present state and considerations of the future. The Aged Care Workforce survey, 2016 (Mavromaras, et al., 2017), estimated that there were 130,263 workers in home care and home support organisations, and 86,463 workers in direct care roles which was a 7 per cent decrease from the 2012 survey. This converts to a 19 per cent decrease on an FTE basis, an indication that attention is needed here.

The characteristics of these workers were:

- 89 per cent female;
- Median age 52 years;
- 84 per cent are Community Care Workers (CCW);
- 23 per cent born overseas;
- 75 per cent employed on a permanent and part time basis;
- 14 per cent are casual or contract employees (down from 27 per cent in 2012);
- 75 per cent of workers engaged in work-related training (mostly mandatory) in the previous 12 months;
- 48 per cent of workers undertook continuing and professional development.

The community care workforce has been getting older while the residential workforce has been getting younger. A much smaller proportion of CCWs than other occupations in home care and home support undertook training or continuing and professional development. There was a lower level of work-related training than in 2012 suggesting that, as well as a decline in numbers, there is a training gap to address. The authors also report that negative perceptions of aged care work as an occupation of low pay and status remain. The Productivity Commission estimates that by 2050 the aged care workforce will need to have grown to 980,000 workers by 2050 (Productivity Commission, 2011). Given the need for expansion of the aged care workforce, the negativity issue needs to be addressed as a factor in meeting the demand for more skilled workers.

<sup>5</sup> This chapter was co-written with Dr Anne Jones, Victoria University, Melbourne.

## 7.2 The need for training

Specialised training in working with elderly clients is important for all workers, specifically for:

1. Personal care workers who engage directly with aged clients in their homes;
2. Service provider organisations and their administration staff; and
3. Volunteers, relatives and friends who provide informal care services.

Rapid growth, coupled with large, disruptive new entrants to the industry, has made this training even more important as providers struggle to keep up with changing care models and increased competition for skilled workers.

Looking at the informal workforce, when asked about their own experiences of providing care for someone at home, 74 per cent of our survey respondents indicated that they felt they had the appropriate skills for this, while 26 per cent felt that they did not. Of most concern is the 40 per cent who felt that their health was being affected by informal care work. This risk is two-fold:

- The carer may become unable to keep providing care at home for the care recipient who will then need more formal care services or residential care; and/or
- The carer may become prematurely in need of formal care themselves.

Appropriate training is a significant and available action to mitigate this risk. This will require greater attention to the requirements of informal carers than is currently evident.

Everyone who provides services to elderly people, including these informal carers, would benefit from some education in how to work with older people and meet their needs. As well as the health-related professions, other specialised occupations within the industry need training targeted towards aged care services. For example, administrative staff who work with clients on their care packages and budgets require technical knowledge of the package system as well as skills in working face-to-face with clients to support them to make good choices, and, of course, administrative skills that align with their organisational needs.

## 7.3 Current training options

### 7.3.1 National VET qualifications

Many higher education and national VET qualifications are relevant to home-based service provision for elderly people. There are also some specialised VET qualifications specifically developed for this sector. To train personal care workers, the national training system offers the Certificate III in Individual Support which is a cross-sectoral qualification based on a set of core units and clusters of elective units preparing graduates to specialise in disability support, home and community care, or aged services.

For aged services there are also some accredited skill sets providing short training programs for workers who do not need a full qualification. This design can facilitate the transition of workers from one personal care sector to another, for example, with the addition of training in dementia care. The national implementation guide for the qualification states:

*This qualification reflects the role of workers in the community and/or residential setting who follow an individualised plan to provide person-centred support to people who may require support due to ageing, disability or some other reason. Work will involve using discretion and judgement in relation to individual support as well as taking responsibility for own outputs. Workers will have a range of factual, technical and procedural knowledge, as well as some theoretical knowledge of the concepts and practices required to provide person-centred support (Community Services and Health Industry Skills Council, 2015).*

### 7.3.2 Certificate III in Individual Support

For aged services workers, the 13-unit certificate offers seven core units, three aged specialisation units and a large range of elective choices. The seven core units are:

- Provide individualised support
- Support independence and wellbeing
- Communicate and work in health or community services
- Work with diverse people
- Work legally and ethically
- Recognise healthy body systems
- Follow safe work practices for direct client care.

The three aged specialist units of which a student selects at least two are:

- Facilitate the empowerment of elderly people;
- Provide support to people living with dementia;
- Meet personal support needs.

There are over 50 electives available, including many relevant to this study, such as:

- Implement falls prevention strategies;
- Assist clients with medication;
- Promote Aboriginal and Torres Strait Islander cultural safety;
- Facilitate independent travel;
- Provide loss and grief support;
- Support relationship with carers and families.

The Individual Support Skill Sets are:

- Facilitate the empowerment of elderly people;
- Provide support to people living with dementia; and
- Meet personal support needs.

The Home and Community (Ageing) Skill Set consists of:

- Facilitate the empowerment of elderly;
- Meet personal support needs;
- Support relationships with carers and families; and
- Provide home and community support services.

### 7.3.3 Certificate IV in Ageing Support

Those with more complex roles may undertake the Certificate IV in Ageing Support. The national skills website, Training.gov.au, states that this certificate is intended for roles such as:

- Community Program Coordinator
- Residential Care Worker
- Support Worker (Community Services)
- Care supervisor
- Accommodation Support Worker
- Personal care worker
- Personal care giver/assistant
- Residential care officer
- Day Activity Worker
- Care Team Leader (Australian Government, 2015).

The Certificate IV provides a wide range of specialist aged services units as well as administrative and management units.

The units available in these national VET qualifications have the potential to address many of the service needs identified in this study. However, the data on consumer experiences gathered from the survey and interviews indicate gaps in content and/or in delivery/assessment and context. The latter two parameters are hard to gauge without further research into how the qualifications are taught, considering what qualifications are held by workers in the industry and how well these have prepared individuals to work with clients. Employers have experience of, and views on this, which indicates the importance of good skills training. In interviews, care workers themselves agreed, saying:

- (1) *For tasks where higher skills are required, we recruit Certificate 3-4 staff only from reliable agencies. They need to be from a reputable training organisation and a 'good fit' for us.*
- (2) *(The girls) are thrown in the deep end after only one day with an experienced care worker ... It's in the Award that they only get one day with a care worker before working on their own. If I tell my service coordinator that someone needs more training (more than one day) she follows it up.*

## 7.4 Training lags

In this dynamic, emerging aged care services industry, qualifications need to keep abreast of changes in industry practice and policy requirements. Alongside changes to government policy settings that signal a clear shift from residential to home-based care, many factors point to significant workforce transformation over the coming years. A consumer-centred approach, with services tailored to diverse needs, will require service providers and employees to strengthen and broaden their skills and competencies. Flexible training delivery options will also be required. Industry needs to co-design the education system with educators and consumers to meet these future challenges in skilling and training this exponentially growing workforce.

Currently there are lags in the system for developing national qualifications following major changes. The interplay of interests with differing views on the industry operating model is making qualification currency very difficult to achieve. The Australian Industry and Skills Committee (AISC) is establishing an Aged Care Industry Reference Committee (IRC) which provides the opportunity for a fresh approach to these issues (Aged Care Industry Reference Committee, 2018). Further, there is an opportunity to drive a more positive view of aged care services with a skills uplift and training boost.

## 7.5 Training gaps from the client/care worker view

Aligning curricula with the reported experiences of consumers and their personal care workers indicates clear areas of underperformance and potential skill gaps.

### 7.5.1 Cleaning

Dissatisfaction with cleaning provided within packages was the common flashpoint for consumer dissatisfaction with their care experience, as discussed in Chapter 4:

*I felt some of the services were slap stick, i.e. cleaning with no real commitment. Nursing services were good.*

Cleaning skills are not included in the Certificate III intended for home-based carers, and the cleaner role has an ambiguous status within service models:

*You must remember we're not professional cleaners. We only do it if it's for everyday living. Some clients expect too much e.g. they want the care worker to get up on ladders and clean out the gutters. But some care workers abuse the policy which comes back to their training.*

Providers have also considered whether personal care workers should be doing this. One provider indicated their approach to this:

*We use professional cleaning services not our family carers to clean. Carers can only do light work however they must change bed linen, which is one of the hardest things for older people. We recommend that they use their Package for a super clean twice a year to keep things under control.*

This decision comes from a strategic analysis that cleaning inhibited flexible, client-centred care and that it was a skilled professional task for which others were better trained and more cost-effective. If home-based services are using personal care workers as cleaners, they could consider providing training including access to units from the national Certificate II in Cleaning (Australian Government, 2017).

### 7.5.2 WHS confusion

There was considerable confusion around what could and what couldn't be done in cleaning and housework which in some cases consumers found absurd. Some workers seem to have rigid rules to follow, for example, nothing to be lifted above shoulder height, or they can't carry things upstairs, while others were more flexible, for example, one care worker said she was directed to lift nothing over 20kgs but is told to make her own choices. It isn't clear if this was the consequence of training or organisational regulations. One care manager pointed out her preferred method for assessing such risks as part of care planning:

*I wouldn't have a carer, physio, cleaner go into a home unless I've been in the home myself. I do risk assessment. I think it's mandatory.*

Safe Work Australia were contacted for clarification on the issues raised in the data on WHS restrictions. Safe Work Australia leads the development of national policy to improve Work Health & Safety (WHS) and workers' compensation arrangements across Australia. They have developed a set of model WHS laws but do not operate as a regulator. State regulators have specific information related to the health and community services sector. WorkSafe Victoria, for example, state that aged care workers have a higher than average chance of being seriously injured at work, and more than 64 per cent of injuries are caused by hazardous manual handling and slips, trips and falls. Costs associated with claims in Victoria from 2012 to 2015 were over \$115 million (Victoria State Government, 2018). In home care, WorkSafe Victoria state that 80 per cent of injuries are musculoskeletal injuries that are preventable (Victoria State Government, 2018).

According to the WorkSafe Victoria Home care – occupational health and safety compliance kit, the following seven hazardous tasks are the most common causes of injury in the home care sector, with awkward posture and repetitive movements being the main issues:

- Vacuuming
- Mopping
- Showering/bathing client
- Moving client
- Cleaning bathrooms
- Making beds
- Use of vehicles (Victoria State Government, 2011).

For vacuuming, for example, WorkSafe Victoria regard lifting the vacuum upstairs and moving furniture, rugs, mats and other items in preparation for vacuuming to be two sources of risk. They recommend that the home care worker avoids vacuuming stairs, ensure tasks involving similar movements are not performed for more than 30 minutes at a time, and ensure vacuuming does not occur where heavy furniture, rugs or mats need to be moved. Workers who refuse to move furniture to vacuum are clearly operating within these guidelines. Consumer complaints received for this study, however, most often relate to light furniture such as dining chairs. The refusal of care workers to move such items when cleaning causes considerable frustration for consumers of home care and home support, and many choose to end their services. More work is needed to clear up WHS confusion in the sector, with some kind of national consensus position needed, working within the safety framework.

### **7.5.3 Personal carer training**

There is a clear training gap for people working as personal carers who don't have aged care qualifications. One provider reported to us:

*We don't necessarily recruit Certificate trained workers for lower level companionship and personal care, particularly where there are no medical issues involved.*

This is common across the industry and usually covered by on-the-job training of varying quality. Apart from reported incidents with care workers who appeared unsuited for the work, this was not like cleaning and wasn't a flashpoint for consumers.

Eighty-eight per cent of the current aged services workforce has post-secondary qualifications (Aged Care Services Australia, 2016), but it appears that many of these hold qualifications that are not employed in aged service provision. This provides an explanation for why the workforce has grown by over 58,000 workers in eight years (p.4), whilst the numbers in relevant VET training have declined as is also reported in The Aged Care Workforce, 2016 (Mavromaras, et al., 2017).

#### 7.5.4 Dementia and related illnesses

The unit, 'Provide support to people living with dementia', is available but not mandatory within the aged services specialisation skill set. A lot of personal care workers will not have been trained in dementia care because:

1. Specific personal care training is not mandatory, and many personal care workers have not completed relevant qualifications; and
2. Those with relevant qualifications may not have elected to undertake the unit on supporting clients with dementia.

There is a case for such training to be compulsory for everyone who provides personal services to the aged. One man expressed how grateful he was for the carers who were trained in this area:

*While my spouse was being cared for in the home, I found that some of the carers seemed to have no understanding or training in caring for someone with dementia. For the ones who were obviously well-trained in this area, I was truly grateful.*

A care worker acknowledged the challenges of the job but indicated she feels able to rely on her training to deal with any issues that arise:

*I have had difficult clients – but I have policies to follow. I'm trained to deal with these things. You must remember you're dealing with sick people. I don't go to someone's house to be abused or yelled so I don't like that, but I put myself in their shoes and try to understand what they're going through.*

#### 7.5.5 Access to training for informal carers

With a third of carers not feeling skilled enough for their work and 40 per cent feeling that it's affecting their health, should there be face-to-face and virtual training kits for relatives and friends who provide care? Should clients, relatives and friends undertake inductions followed by refresher sessions (face-to-face or virtual) on how the sector works? As well as protecting them from health risks and enabling better care, this could also educate them about the care system so they can use it more effectively.

Quite a few respondents commented that they had nursing qualifications, or formal qualifications and experience working in the aged care sector before providing informal care for their parents:

*I am a trained nurse so I felt I was able to cope quite well. I looked after my mother full-time in my own home for approximately 10 months.*

One respondent with a nursing background believed her qualifications were necessary for the informal care she provided:

*I have a nursing background and I needed every skill I had ever learned to manage care for my parents at home.*

In a future scenario where higher level packages substitute for residential care, the need for skills training for informal carers will become more acute.

## 7.6 Care worker selection

The Aged Care Workforce Strategy Framework states that about 15 per cent of care workers are aged under 25 (Aged Care Services Australia, 2016). The National Centre for Vocational Education Research (NCVER) age rates for those in training are different (National Centre for Vocational Education Research, 2018). Their data shows that for the three years 2014-16, a total of 372,857 people were training to become personal carers (this includes people preparing for the disability and community care sectors as well as aged services). Of these, 16 per cent were aged 19 and below, 14.7 per cent were 20-24, 42.3 per cent 25-44, and 27 per cent aged over 25. In either case, there seems to be a pool of potential workers aged 25 plus. As already noted, the numbers in training in the skills sector don't match the recent growth in employment in the industry. One manager from a large TAFE institute that delivers this training, explained that the industry is not committed to training because of the costs involved and, consequently, there are many without formal training in the active workforce.

Problems attributed to care worker age and related attributes may have as much to do with selection processes and organisational culture as training. For example, the problematic young workers may not have been trained, may not have been carefully selected for their role, and/or may be working in a culture that doesn't support them to provide attentive, respectful services. Added to this are the pressures low wages place on the stability of the aged care workforce (Productivity Commission, 2011).

## 7.7 Care planning

There are planning, management, and service design skills needed to assist clients to make choices within the more complex packages. A good care plan carries the 'DNA' of Consumer Directed Care, and adapts over time to client changes and different preferences. This requires considerable skill. There are signs of an emerging niche for service design and plan managers with the skills needed to assist clients to make choices within more complex packages. This role could include the negotiation and mediation needed to support recipients and family members to reach agreement on care choices.

*This is the care manager role – we deal with the family. When (the client) receives packages Level 1 to 4, we work with the family to work out how the money can work best for the family member to keep them at home. You work with the family every day sometimes. On Level 4 they have more money so they can have more carers, physios, and cleaners, so we can put a budget together to allow them to stay as independent as possible in their home.*

This indicates that the VET sector should consider the inclusion of personal advocacy and advice skills, as well as the broader skills of care planning, within aged and community services qualifications.

### 7.7.1 Personal advocacy and advice

Advocacy and advice are core elements of care planning but are provided by established providers large and small without committed funding from packages since this usually comes before the care plans are developed:

*A lot come in bamboozled by the MAC system, grateful to have someone to listen and give them guidance. People are also bamboozled by the costs ... Many are afraid to do the income and assets tests for fear of their home being taken away – their inheritance. They have lived in their home 30-40 years and want to die there.*

In the Consumer Directed Care environment, independent advice is critical to the functioning of the model. This requires access to knowledge beyond their immediate service provision and understanding and avoiding of conflicts of interest. Training is needed for these skills.

## 7.7.2 Family dynamics

For the care planner and the service provider, issues arising between adult children and their elderly parents need to be taken into consideration. Sometimes other family members will have to be considered in planning and providing services:

*The relationship with (some of) my brothers and their families seemed to fracture. Advice given to me by friends and acquaintances was that this is a normal phenomenon as parents age, and to just accept it.*

Difficulties occur when adult children disagree about informal (family) care provision, what kinds of services are needed, or the financial arrangements for their parents:

*My brother was convinced that I was after my mother's money. He accused me in court of parental abuse so her affairs were placed in the hands of the public guardian who proved extremely expensive.*

The following section of one journey story is quoted to indicate the difficulties encountered by family carers and the complexity providing aged care services into the cauldron of family conflict.

*I believe I am not the only one affected by family dynamics and difficult personalities, which present obstacles along the way. My husband and I received a lot of negative feedback for decluttering and replacing furniture. My mother told me the meals I was cooking were not suitable, (but) after a few months (of Meals on Wheels), Mum cancelled the meals (and) frozen meals became the order of the day ...*

*One brother and I had been very close, but stopped communicating as he thought I was doing the wrong thing by our parents. His wife informed me I was not to visit my parents without her permission and I told my brother this was elder abuse. My brother separated from her after that and we reconnected. He apologised and we are now working closely together to ensure our parents receive the care they need ...*

*I noticed my mother's behaviour and comments worsening toward me (and my adult children) the more time I spent with her. My research into narcissism helped me to understand my long term (dysfunctional) relationship with my mother and how best to continue to provide the support and love, to both parents, that was needed.*

Training needs to enable care providers to cope with these dynamics without being drawn into them, and to have strategies when conflicts that inhibit good care are encountered, including when to withdraw 'gracefully' and refer to management. The carer cannot be expected to be a family counsellor or negotiator but they need strategies to continue providing high quality care.

## 7.8 On-the-job training

On-the-job training is universal in the sector with varying degrees of quality and intensity, as there continues to be widely varying service models and organisational cultures. One of the smaller, boutique providers who participated at all levels with interviews explained their intensive approach to on-the-job training as a part of a process of change and growth.

*Our client-directed process has required internal education from the top down including the Board. They are fiscally responsible, but the key decision determining outcome is 'higher client satisfaction' and added value, not profit.*

*This culture is carried by the middle management, but most importantly, they had to train the families to know what the current and new rules were. The client satisfaction focus had to be carried by cleaners, phone answerers, and everyone through the organisation. This took six months training and education in large and small groups. Those who found this difficult were buddied up with someone who did get it. This ethos has always been there from our community origins. This was just fitting this into a new and changing environment ...*

*The call centre was not well trained but a critical point. They were taught to think about what they're saying to clients, get their medical history and find out what they wanted and to create this as a picture for them to take to the RAS to get what they wanted. It was simple but thorough training about telling people what the things were and explaining the process better ...*

*We do continual fast training so that we are client-focused. You might be a Certificate 3 but if you have ideas, tell us. It's their job to get to know the client and find something that will enhance their life. This requires an openness to the client. If you tightly roster care so it must finish before 9:05am, no relationship can develop. Families are stressed and sometimes things will be out of control. We train workers to stop, sit, 'take it on or refer it on' ...*

*You need to be constantly learning in any field, you need to be 'involved', listen especially in aged care – listening and learning.*

This case study also demonstrates the importance of organisational design and culture as determinants to the service models used by providers. Certain elements, like consumer focus and direction are shared but it is the approaches that differ.

## 7.9 Management

Within such a diverse industry with so many providers, there is clearly a need for improved management skills. Organisations, small and large, have the equivalent of a large sales force team out in the community, sometimes without the management structures and systems to support them. Consumers were often very critical on the management behind their providers and there are clear lessons from this.

Perhaps the greatest factor for the future is that, without better management, providers will not be able to retain skilled and motivated workers, as one expressed this:

*The thing that encourages workers to stay in the industry is good support in the office.*

## 7.10 Mandated courses

The Aged Care Workforce 2016 reports that a much smaller proportion of Community Care Workers than other occupations undertook training or continuing professional development in 2016 than in 2012 (Mavromaras, et al., 2017). The National Quality Framework for Early Childhood Education and Care was introduced in 2012 (Australian Government, 2018). Child care workers are required to have a Certificate III in Early Childhood Education and Care and a Working with Children Licence. It is debated whether mandated skills training has raised the quality of work and retention of workers. Research is unequivocal on the link between staff qualifications and training and improved outcomes for children in early childhood education and care programs. A 2008 literature review of quality in child care concluded that across age groups and service settings, “the most significant factor affecting quality appears to be caregiver education, qualifications, and training” (Hunstman, 2008). It is certainly worthy of debate whether some level of training in aged services should be mandated for workers in this sector and, if so, for which roles. Aged care workers could be required to have the Certificate III, and other staff coming into regular contact with aged services clients could be required to complete the three Aged Specialisation Units, for example, including dementia care. Employers would want to see the cost-benefit calculations for this but there may also be other benefits such as giving the industry a more positive public image with better and higher skill levels.

## 7.11 Where to from here?

Education and training for workers in the aged services sector must change to accommodate the new service environment. Improved education and training for workers in the sector are critical to achieving better outcomes for older people and for the organisations supporting them.

From a skills development perspective, the sectoral trends that are influencing training include:

- Consumer Directed Care affecting the range of services offered and the ways in which these are delivered;
- Expansion of the sector as the baby boomers increase the proportion of aged in the community;
- Increased life expectancy and health changing client expectations of outcomes from services, e.g. a focus on reablement rather than chronic invalidity;
- Marketisation as new players move into aged services provision, leading to new employment modes which in turn will require workers to respond with new capabilities, e.g. more self-employment requiring entrepreneurial skills.

These changes are imminent and a review of education and training for aged services workers is urgently needed. This is a matter that is likely to come to the, soon to be established, Aged Care Industry Reference Committee (IRC).

### 7.11.1 Higher quality training

Clearly, it is important for course providers to be delivering and assessing the training in an authentic learning environment, with access to actual or high-quality, simulated home care locations. The training needs to be dynamic and situated. It is important to involve good providers who can implement high quality experiential learning to ensure that workers are well-equipped to deal with the complexities of care work in client homes. Since considerable resources have been developed to deliver these qualifications, it also makes sense to consider how the existing constituent units can be used, with or without rewriting or repackaging.

Further attention needs to be given to the currency and qualifications of the teaching staff. It is obvious that, without good quality teaching staff with current knowledge of the system, more education and training will be less effective.

It is difficult to separate the influences of organisational culture and people management practices from the impact of training. This is especially difficult in the absence of good data on the training histories of carers and other workers in the sector. Given that provider organisations are doing significant on-the-job training, there is an opportunity to avoid this division of labour and support better on-the-job and face-to-face training in the workplace. The technologies are potentially available for this to work immediately, which means the resources are in place to quickly make a difference to the skill levels and breadth of skills in the workplace.

Given the importance of aged service administrators and care workers learning in authentic environments, on-the-job training of the type described in our case study provides an ideal learning environment for practical skills development. Acquiring some types of knowledge is more difficult, for example, understanding dementia or the complexities of government funding packages. For this reason, the traineeship/apprenticeship system combining on-the-job training in real workplaces with off-the-job learning could be expanded to meet the future learning needs of care workers and their front-line managers. Employers, especially SMEs, may not be able to resource traineeship learning and in such cases the group apprenticeship model or very high-fidelity simulated care environments may be used.

### 7.11.2 Intersectoral skills

Intersectoral skills between health and aged care services are much discussed as a priority for the future. The capacity for such skills across community care and hospitals is likely to develop slowly with the improvement of core skills and numbers in the workforce. The ideal is to have people who have worked across both sectors, which will always be a hard recruitment option. Intersection with the allied health sector is already common, and this area is one where skills, particularly around communication and referral, need to be maintained. These are important particularly when there is a sudden escalation in need after access of the health system, which itself was poorly coordinated internally. One family felt this decline should have been noticed and communicated to them and community carers so that their father's care could have been better coordinated:

*There is very little to no communication between the various medical facilities, specialists and professionals resulting in missed information and/or appointments being doubled up and having to be re-booked.*

The lack of integration of medical care for aged people is not only a burden on the health system, but results in premature entry into residential care:

*The likely outcome of these experiences is that he will have to go into residential care, since we can't keep going on this roundabout. This will probably be before it's really needed.*

The medical care workforce is larger, better paid and more highly skilled than the aged care workforce, which usually means that the aged care worker has less influence than the hospital. There is a common interest in quality patient care and cost effectiveness which can be exploited in areas where there is the opportunity to work together. On the other hand, allied health cooperation is already in place and can be routinely part of education and emphasised more since Consumer Directed Care has been introduced.

The demand for these specialist skills will increase rapidly as more higher level packages are put into the market and more dependent clients remain at home.

### 7.11.3 Review of national qualifications

The national qualifications are an important resource for the industry. Qualifications such as these are used to ensure minimum quality standards in many industries including children's services and the registered trades in Australia. In a volatile and complex employment environment these qualifications also give individual workers a portable credential providing evidence of their capability to work in the sector. It would improve the current skill base if:

- All workers engaged in face-to-face services provision to aged clients acquire the Aged or Home and Community (Ageing) Skills Set;
- All care assistants be required to have the Certificate III in Individual Care;
- All team leaders and others in frontline management roles undertake the Certificate IV in Ageing Support;
- Teaching staff qualifications and currency are regularly reviewed and improved.

The evidence from consumers and future foresight indicates a clear need to review the fitness of these qualifications to prepare aged services workers for the client-directed care world. It is important now to know how well the qualifications prepare workers to:

- Be capable of supporting ageing as a positive rather than a negative experience;
- Support enablement;
- Be adaptable and able to respond flexibly to new client requirements;
- Advise clients on complex policy and funding changes;
- Work respectfully and emphatically with a range of clients including Indigenous Australians and various migrant groups; and
- Be capable of work with clients with disabilities and conditions such as dementia.

### 7.11.4 Shorter courses

In the aged and disability services industries, some employers are reported as saying that they can't afford to pay for workers to undertake a Certificate III and want something shorter. Dementia training fits well into this model. Later career stage entrants would benefit from this style of training since they are likely to have existing skills. The VET sector could expand the range of units available as skill sets leading to micro-credentials that may be accumulated to a certificate or diploma qualification for those who desire or require that credential.

### 7.11.5 The Skills Escalator Model

The Aged Care Roadmap proposes to leverage Government programmes to boost labour supply and developing carer structures and pathways within aged care (Aged Care Sector Committee, 2016). An innovative approach to this can be found in the Skills Escalator approach in the British National Health Service where it is one of their four pillars for Human Resource Management. The model merits consideration because of its fit to the aged care services workforce composition and issues (Department of Health, 2007).

The essence of the Skills Escalator approach is that staff are encouraged through a strategy of lifelong learning to constantly renew and extend their skills and knowledge, enabling them to move up the escalator. Meanwhile, efficiencies and skill mix benefits are generated by delegating roles, work and responsibilities up and down the escalator. This is a future vision for aged care and related services where there is a matrix of skills and roles which people can move within flexibly with formal and on-the-job training. This will require detailed mapping of skills and cross links across occupations, not exclusively to the care service industries, but also closely related work such as hospitality and sales.

The Skills Escalator attracts a wider range of workers by offering a variety of step-on and step-off points. Traditional entry points such as certificated staff continue but they are complemented by other entry routes such as trainee and cadet schemes and role conversion, attracting people in other careers who are seeking new challenges and drawing people back into the labour market. This offers the dual benefit of growing the workforce whilst also tackling problems of unemployment and social exclusion. An active example of this is bringing immigrant women into birthing support roles and skilling them to take on care assistant and assistant nursing roles and, then, to higher level qualifications.

It will enable people to start or further develop careers, as young people starting out or in mid- or later-life as a second career. It is able to help manage diversity by bringing in workers with specific language and cultural skills to service diverse clients. Age, background and existing academic attainment should not be barriers to those with the potential and will to progress their careers. It can also facilitate having a workforce that is more representative of local communities and in touch with their needs.

### 7.11.6 Opening courses to informal carers

The glaring gap in the training provision is in the services provided for informal carers who provide for the needs of family and friends at home or in their homes. In this study, 33.8 per cent of respondents indicated that they provide home care to someone else. Whilst the majority feel they have the skills to provide the care, they may not have the skills to provide it efficiently and safely. Some 40 per cent, for example, feel that the provision of care is affecting their health. This can be addressed by opening existing courses to informal carers and by promoting high quality online training. For informal carers the training must be accessible and low cost. Given the public contribution made by them, the cost-benefit would justify free access to training.

According to ABS data:

- Over a third (34.1 per cent) of primary carers had been caring for 10 years or more;
- Of the 299,300 primary carers who provided care for more than 40 hours on average per week, 28,400 primary carers (9.5 per cent) had been providing care to their recipient for more than 25 years;
- The workforce participation rate of primary carers was only 52.6 per cent compared to nearly 80 per cent of non-carers (ABS, 2012).

There is, therefore, the potential for carers and former carers to become a potential source of recruitment to grow the aged care workforce. Carers acquire many skills in their caring role and for some years now Carers Australia has been advocating for either:

- Changes to existing mainstream government programs which assist job seekers into employment to be more responsive to providing intensive assistance to carers wishing to re-enter the employment market; or
- A specialised program dedicated to this goal (Carers Australia, 2016).

A broader Skills Escalator including carers and former carers is well suited to meeting these needs.

## 8. FINAL THOUGHTS

### 8.1 The ‘burden’ of care?

The evidence is that Australians do not regard the later stages of life positively (McCallum & Rees, Growing older, feeling younger, 2017) and care work with the elderly is negatively regarded (Mavromaras, et al., 2017). This leads to barriers to recruitment, quality, and retention for the aged care services workforce. By comparison with aged care, we would not regard the work of a bowel cancer medical specialist with the same negativity. There is a clear degree of skill difference here but the work is hardly clean and pleasant. It has difficult parts, like aged care services. This points to a key factor leading to negativity and sense of burden about services related to ageing, namely the level of skill which gives a status level to an occupation. The more skill and training, the more highly regarded the occupation. This provides a direct argument for the need to upskill aged care services, which had good consumer support. It can create pressures for higher wages, which is also supported by some consumers.

*With an ageing population, we need qualified carers, who are in my view, special people, as I for one, would not be able to cope, and I think those who look after needs of the aged should be paid well, perhaps more than a nurse on a ward in a general hospital.*

Some informal carer comments indicate that care is often perceived as a burden. There is also an implicit expectation that the government will pick up things when needs are beyond family capabilities, and consequent dissatisfaction when this doesn't occur or is difficult to arrange. We have previously observed that only 3 per cent of respondents to a 2017 survey were planning to spend more money in later life than earlier or spending the same throughout and hoping that it lasted through a longer life (McCallum, Maccora, & Rees, Hope for the best, plan for the worst? Insights into our planning for longer life, 2018). This was in the face of clear evidence that this is the time of life when care is going to be most expensive and that government can't do it all.

This negativity towards the ageing phases of life is also continually reinforced by the media feed into the public debate. The same has occurred over the last few decades in child care but it is not the case that child care is regarded negatively as a burden. It may well be burdensome, but this is usually regarded positively and accepted as a natural life stage. The negative media reports on child care have had a more positive public reaction with emphasis on skills, education and salaries which is a lesson for aged care services. Australians have not regarded child care as an area where government should be the major player and automatically step in and help. This is now changing, driven by the positive benefits of enhancing employment issues for women. Such positive reactions are yet to be achieved for aged care services.

### 8.2 People who don't feel it's a 'burden'

On the positive side, it's also true that many current workers and informal carers don't feel this in any way. An indigenous care provided was absolutely devoted to her role:

*I'm 53 now and I've been doing caring all my life but I've only been getting paid in last 10 years! Up until then, I wasn't at all happy. I was very lost. I prayed a lot and a couple days later Aboriginal woman in our care service asked me if I wanted to work as a care worker. I applied, got the job and things turned around for me. I love my work. I will go and go till over 60 at least. I couldn't get a better job. The people I care for really need help.*

Many also commented that being a caregiver is satisfying:

- (1) *It was self-satisfying that I was able to provide personal care with a touch of love to a loved one.*
- (2) *I nursed my mother for about six months before she passed away from stomach cancer. She moved into our home and it was an amazing experience for my husband and it was a real blessing to be able to care for her at home. She passed away in our home.*
- (3) *Sometimes love, not skills, get us through.*

Communal cultures, evident for example in new immigrant groups, do not regard caring as a burden but as a duty. Whilst this can be a more positive view, it may have the same impacts as regarding it as a burden namely family conflicts, impacts on marriages, and mental health.

The important objective now is that through training and better management of services we can increase the numbers of people who regard caring as a 'blessing' and a positive experience associated with ageing. This is also the aim for the sector in the Aged Care Roadmap, which needs more action.

### 8.3 Positive creativity in care

We are expecting a disruptive period in the aged care services industry. Rather than a negative, this will require more innovation, higher and different skills, and demand creativity. Managers are aware of this.

*The release of power to client is too hard unless your well trained and prepared to use every aspect of your creativity.*

Examples of this creativity have been presented in quotes:

- (1) *A client a long history with music should mean that managers get them to concert programmes, and drop the plan for that week. Music before dusting for a week.*
- (2) *The task is not simply to fix a broken toe but to enable someone to get out of a chair.*
- (3) *Take the case of a husband with severe dementia cared for by his wife in her 90s. He wouldn't touch meals on wheels. The Certificate 4 care provider was herself getting frustrated with the situation. She knows that his wife says that going to their favourite Café makes him quiet. His wild aggression disappears. They have a routine where he counts money. So, the decision was made and negotiated with the Café to give them a hot meal once a day, 'tender loving cuisine' as their main meal and they leave with a sandwich and salad for the evening meal. All official standards are being met and the aggression is gone.*

The creativity in finding solutions to complex problems provides a high level of satisfaction for the provider. This will also require good skills training to be applied in the process. Understanding dementia from its organic base to expression in changed behaviour is an interesting and useful educational focus. This knowledge can be applied to care, and case studies can be used to demonstrate this creativity in action. This provides a natural positive emphasis and intellectual challenge to the tasks of care.

## 8.4 High touch innovation

The discussion of innovation in aged care services has been captured by digital and assistive device innovation. Whilst recent digital innovations have become pervasive in work and home settings, they have their limitations and negatives. Perhaps the most resistant 'analogue' has been the book which is still a preferred option vis-à-vis the digital readers and, in some areas, growing in popularity. There are increasing negatives as well, including, privacy, security and cyber-crime, even terrorism. What has been lost is the value of 'high touch' research and development in the care services industries. The most current example of this is in the competition between retailers in shops and centres and the online sales companies. High touch service is one way of providing competition with low cost online sales. The response is for online providers to improve the personal touch in their services.

Similar competition will come to aged care services with disruption. One difference is that there is a digital divide which will take a generation to work through. First, many people now 70+ are not online, while other people are online but prefer to use personal services, and text or analogue options. There is a high degree of learning and service resilience that is required to cope with working online and this will take time to take hold amongst current consumers.

Among other initiatives, LASA has established *innovAGEING* to facilitate a connected community of practice for progressive thinkers, practitioners and innovators in industry, to create, capture and share examples of age services innovation in Australia, and promote innovation within the industry and across the wider community, as well as celebrate, highlight and elevate innovation through a major national awards program (LASA, 2018). Such initiatives as this and the Wellness Economy of the Economic Development Board of South Australia, with a strong focus on co-design, can lead the way in this area.

## 8.5 The five Taskforce Imperatives

1. **Why this industry matters** – Extensive consumer views and reports of the experiences of their immediate service providers indicate how much people need these services, want them to work well and are grateful to have access to them. Care of the elderly is the touchstone of a humane society, which is why the media get such a big reaction to their negative stories. Aged care services matter!
2. **Industry leadership** – Industry mindsets and accountabilities are revealed here through the experiences of consumers at the point of service delivery and through analysis of change and innovation. This is already under significant challenge with the introduction of Consumer Directed Care, and will continue, with further disruption predicted. The effects of this are not as pronounced in consumer experiences as they are for service provider organisations.
3. **Industry workforce** – Consumers and their immediate service providers pointed to clear education and training issues, and lead to a vision for future needs. The coherence skills training and development of new skills will depend on industry working closely with educators and the new IRC.
4. **Employment choices** - The negativity in many consumer comments and stories of their service journeys indicates issues that need attention to give workers more positive employment choices. Without more positive views and experiences of aged care services, recruitment and retention in the industry will struggle. There are many positive options such as improved skills, closer engagement with communities, and positive innovation in technology and personal care.
5. **Ways to develop, sustain and adjust models of care** – Preferred models of care are evident from the experiences of consumers with different service encounters and different providers. They are also being imagined in new technological developments. There is currently a preference for 'high touch' care among consumers which can be delivered with digital and other technologies now and more extensively in the future. It will, however, be another generation before this is widely accepted.

## 8.6 Conclusion

This study into consumer experiences of aged care at home identified the following training gaps:

- Cleaning – if personal care workers are to be used as cleaners, perhaps access to units from the Certificate II in Cleaning would be suitable;
- WHS clarity – the workforce currently interpret Work Health & Safety regulations in different ways and clarification is needed;
- Dementia training is not currently compulsory;
- Increased access to training for the informal carers – some indicate they don't have the skill for caregiving or that it's affecting their health;
- Increased support of under 25s entering the aged care workforce, particularly if providing high level package care and when working with dementia patients;
- Care management roles – provision of advocacy and advice skills by the VET sector, including strategies for dealing with family dynamics;
- Ongoing professional development to continuously upskill the workforce, including on-the-job training;
- Possible mandated courses for aged care workers, for example, a Certificate III.

Education and training programs for workers in the aged services sector need to accommodate a growing and changing service environment. The following potential areas of focus have been identified in this report:

1. **Higher quality training** that combines on-the-job training with off-the-job learning in a traineeship/ apprenticeship system. A service provider case study indicates a model of care provision and management that reveals a strong client-directed, organisational culture.
2. **Intersectoral skills** between health and aged care services are a priority for the future. These are important particularly when there is a sudden escalation in need after access of the health system.
3. **A review of the national qualifications**, for example, to improve the current skill base by ensuring that:
  - All workers engaged in face-to-face services provision to aged clients acquire the Aged or Home and Community (Ageing) Skills Set;
  - All care assistants be required to have the Certificate III in Individual Care;
  - All team leaders and others in frontline management roles undertake the Certificate IV in Ageing Support;
  - Teacher trainer qualifications are regularly reviewed and updated.

It is important now to know how well the qualifications prepare workers to:

- Be capable of supporting ageing as a positive rather than a negative experience;
- Support enablement;
- Be adaptable and able to respond flexibly to new client requirements;
- Advise clients on complex policy and funding changes;
- Work respectfully and emphatically with a range of clients including Indigenous Australians and various migrant groups; and
- Be capable of work with clients with disabilities and conditions such as dementia.

4. **Shorter courses** for employers are reported as saying that they can't afford to pay for workers to undertake a Certificate III and want something shorter. Dementia training fits well into this model.
5. **The Skills Escalator Model** in which staff are encouraged through a strategy of lifelong learning to constantly renew and extend their skills and knowledge, enabling them to move up the escalator. This offers a variety of step-on and step-off points, with traditional entry points such as certificated staff, complemented by other entry routes such as trainee and cadet schemes and role conversion. It is particularly open to the diverse workforce needed to deal with culturally and linguistically diverse clients.
6. **Opening existing courses to informal carers** and by promoting high quality online training. For informal carers the training must be accessible and low cost. Given the public contribution made by them, the cost-benefit would justify free access to training. There is the potential for carers and former carers to become a potential source of recruitment to grow the aged care workforce.

Finally, with an average positive assessment of 65% to over 80% on 7 key quality of care criteria, there is already a strong positive accent to Australian home care at the grass roots. The lyrics of Johnny Mercer, written at the end of World War II, are apposite:

*You've got to accentuate the positive  
Eliminate the negative  
Latch on to the affirmative  
But don't mess with mister in-between*

"Accentuate the Positive" – Johnny Mercer & The Pied Pipers (1945).

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## Forthcoming reports:

Young versus Old? – the evidence (in draft)

Loneliness in Later Life

