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Aged Care's Culture Gap

How to respond to the needs of a diverse and ageing population

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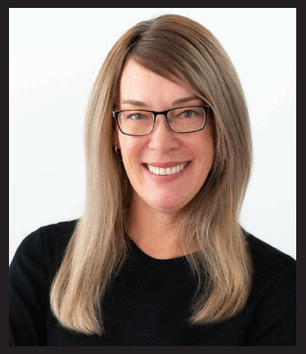
Rick Morton

Rick Morton is an award-winning journalist and the author of three non-fiction books. He is the Senior Reporter for The Saturday Paper. Rick worked as the social affairs writer for The Australian with a particular focus on social policy including the National Disability Insurance Scheme, aged care, the welfare system, religion and employment services. Rick is the winner of the 2013 Kennedy Award for Young Journalist of the Year and the 2017 Kennedy Award for Outstanding Columnist. He appears regularly on television, radio and panels discussing politics, the media, writing and social policy. Rick Morton is also the author of *One Hundred Years of Dirt* (MUP, 2018), the extended essay *On Money* (Hachette, 2020) and *My Year of Living Vulnerably* launched on 17 March, 2021.



Trish Prentice

Trish Prentice is a researcher with a particular interest in social cohesion and religious communities. She has worked in Australia and overseas in the government, academic and not-for profit sectors, including in Cairo, Egypt, working for an organisation specialising in Arab-West Understanding and in Geneva, Switzerland for a human rights advocacy group. Trish has managed research projects in Indonesia, Singapore and Pakistan and written on various topics, including Islamophobia and Australian values from an Islamic perspective. Trish joined the Scanlon Foundation Research Institute in 2020.

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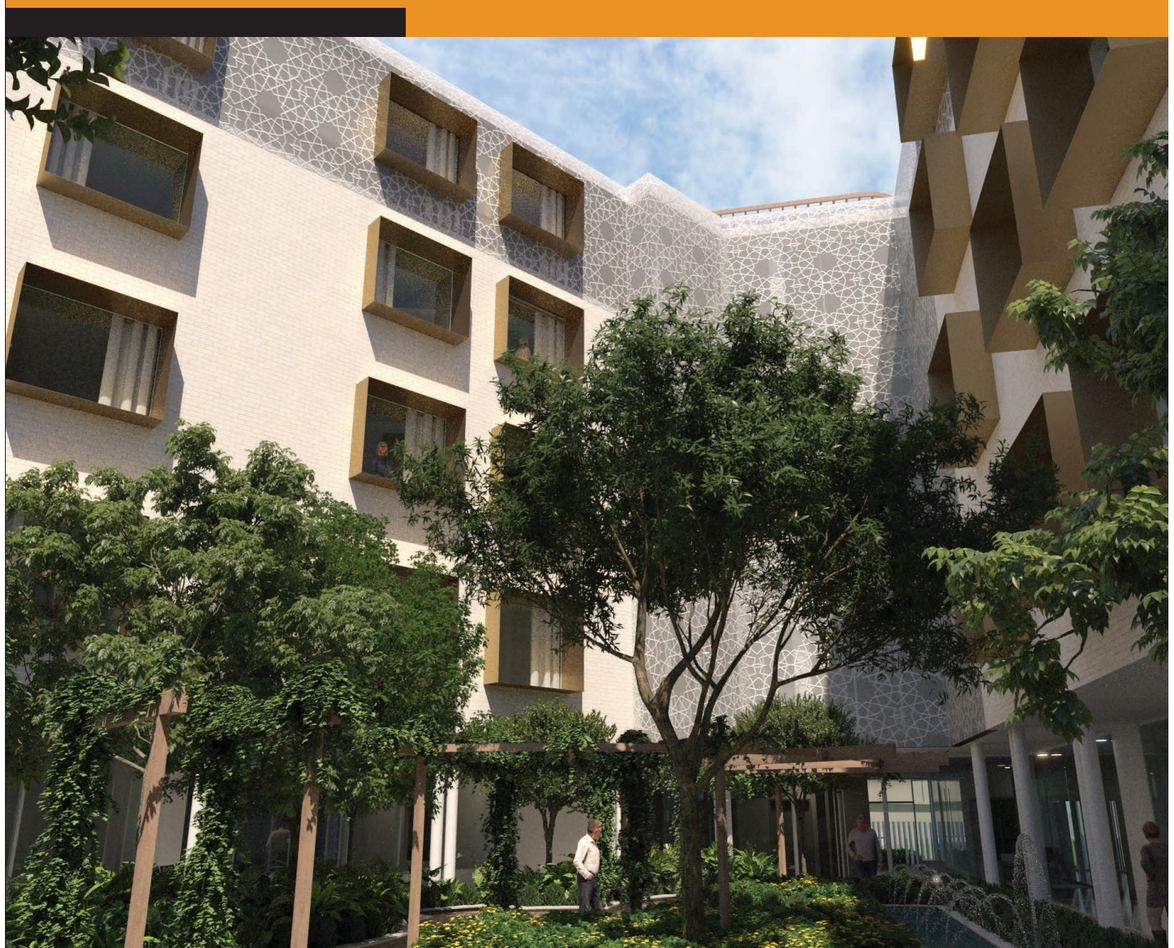


Faduma Jama, a Somali-Australian registered nurse, worked in aged care for half a decade, coordinating clinical care for a network of nursing homes and other services in Melbourne's northern suburbs. In those years she cared for elderly residents from many cultures, and she learnt a great deal about Australia's aged care system — where it works and where it doesn't, and why it so often fails people from migrant and diverse backgrounds.

Jama, who was born in Australia, believes the nation's aged care system fails to recognise that people from minority backgrounds have "a massive aversion to institutionalised aged care."

"I have never come across an elder who wants to be in a nursing home," she says. "I don't claim to know everybody, but it is certainly not something that is normalised in our community.

"Traditionally, the elders are very revered. There is this thing that acknowledges you have worked your whole life, you have raised your family. In some ways it is very similar to the Indigenous community.

"If I came across a random elder, I would call her Aunty or him Uncle. That is just the culture." But Jama says even young people in these communities share that respect for elders and reluctance to use residential aged care. "It is so offensive to them culturally. They think, 'Why would they put their mother in aged care?'"

Yet even members of Australia's Somali community, caught in a pincer between cultural tradition and the pressures of a new homeland, can struggle to deal with the workload, and financial and emotional cost, of caring for the elderly at home.

"There is a failure to recognise that Australia is not like back in Africa," Jama says.

"Back home, somebody would be designated to looking after the elder. The lifestyle is different. Several generations will live in the same home." Large households also make the concept of formal child care redundant except for the "really upper echelons of society."

Jama says she discusses these issues often with Somalis in Australia. “It’s not that people want to put their parents in an aged care facility.” But given that it is not possible to hold onto a way of life that does not exist in Australia, “how do you put food on the table and give your parents the care they need?”

In this painful dilemma for families, Jama sees an opportunity for change — not just for Somali-Australians but for all Australians.

“I still can’t see the business case for why residential aged care is seen as the best model,” she says. “There are massive opportunities for change that works not just for migrant communities but for people from all walks of life, who would love to age in their own homes.”

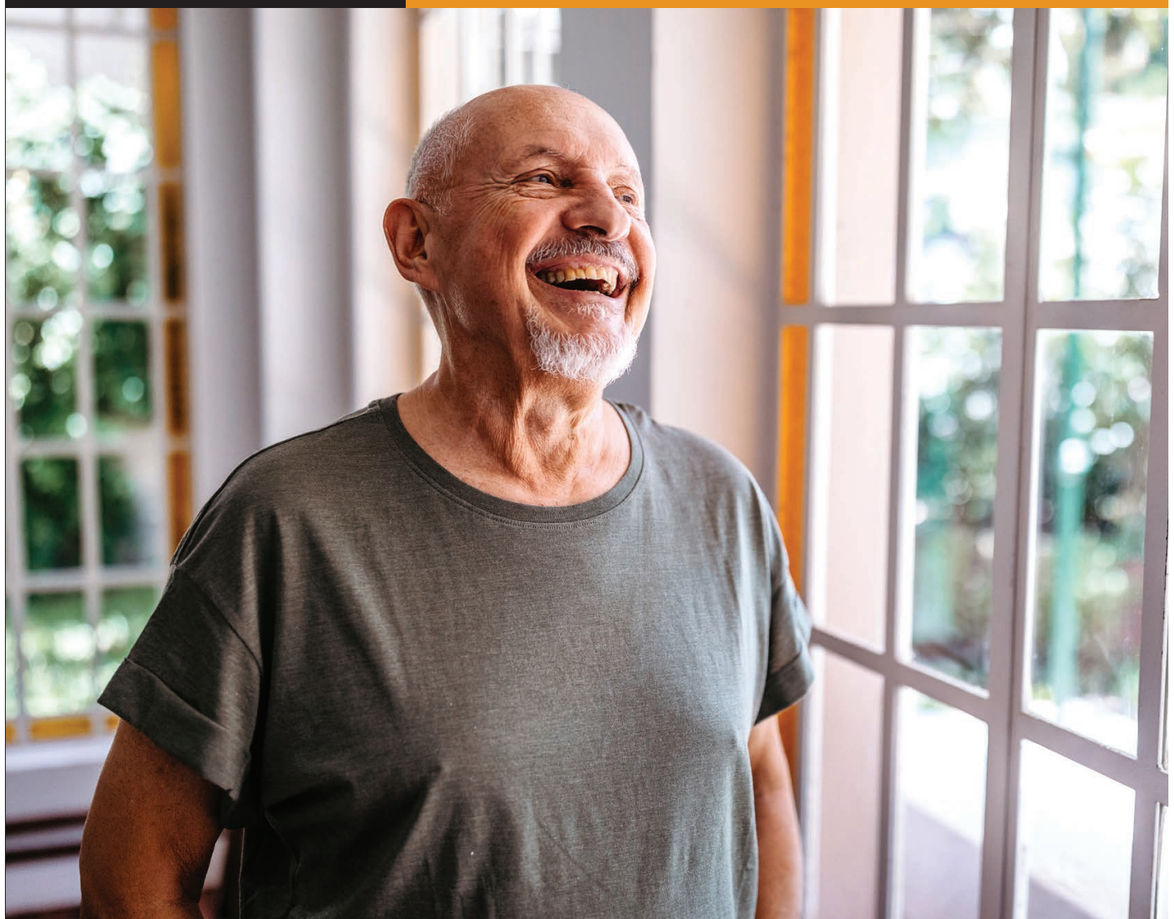
Jama acknowledges that some people have complex care needs or severe dementia. “But for somebody who is just going through the normal processes of ageing, I can’t see why we can’t encourage ageing in the home.” The way to do that, she says, is to improve home care.

Do Jama’s words signal a seismic cultural shift in our understanding of ageing? In western countries, to grow old is seen as synonymous with a diminished life and increased frailty. Such a view may lead us to conclude that seniority itself is the problem. That conclusion would be wrong.

This narrative for the Scanlon Foundation Research Institute examines whether Australia’s aged care system works for elderly Australians from migrant backgrounds. It considers the particular needs and priorities of these communities, and shows how these priorities might lead the way to a better aged care system for all Australians.

For decades now, the principal battle in aged care has been to bring nursing home residents, and now home care support recipients, out of the institutional shadows. Campaigns are ongoing to increase the quality of clinical care and services available in the sector. There has also been a persistent effort to reform the financial arrangements that block care for thousands of Australians. Yet while each initiative has been important in its own way, none is quite so fundamental as the simple yet somehow revolutionary idea that age-related care should not erase the totality of a human being.

The Royal Commission



"The dominant narrative in current Australian culture seems to be that older Australians are a burden. We reject that narrative," said senior counsel Peter Gray QC in his opening remarks to the Aged Care Quality and Safety Royal Commission in 2019.

When the Royal Commission began to hear evidence, the most complex problem it sought to define was how older people are valued across their entire lifespan. To Gray, senior counsel assisting the Royal Commission, that meant Australia needed to create a "culture of appreciation and respect for older people." This was not a case of Australia taking on a burden "but of becoming the nation we know we should be." Crucial to this change was ensuring that "the thousands upon thousands of informal and unpaid carers of elderly parents, partners, relatives and friends" were given the support they needed.

"The work of this Royal Commission will challenge all Australians to reflect on our attitudes to caring for loved ones as they age," Gray continued in his opening remarks. "It will challenge us more generally to reflect on our responsibilities to older Australians whom we've never met but whose contribution has given us so much."

In April 2020, 18 months after it began, the Commission published its final report. Among its tens of thousands of pages are repeated testimonies that residents in aged care homes around Australia are often left unattended or without care for hours at a time. The commission laid bare a poorly kept secret: that homes were increasingly short-staffed, poorly resourced and unable or unwilling to meet basic care demands. Under such threadbare arrangements, older people are warehoused instead of being able to enjoy their later years.

Ultimately, the commissioners found that a near total overhaul of the aged care system in Australia is needed with a new rights-based government legislation, at least $10 billion extra funding each and every year and independent oversight beyond the muddled reaches of commonwealth bureaucracy (which both rations funding and enforces standards). There were 148 recommendations in all, each with a complex layer of moving pieces and although the federal government has agreed in full or in principle with each of these there is no significant attention to workforce pay and conditions, the quantum of taxpayer funding or the rights of consumers.

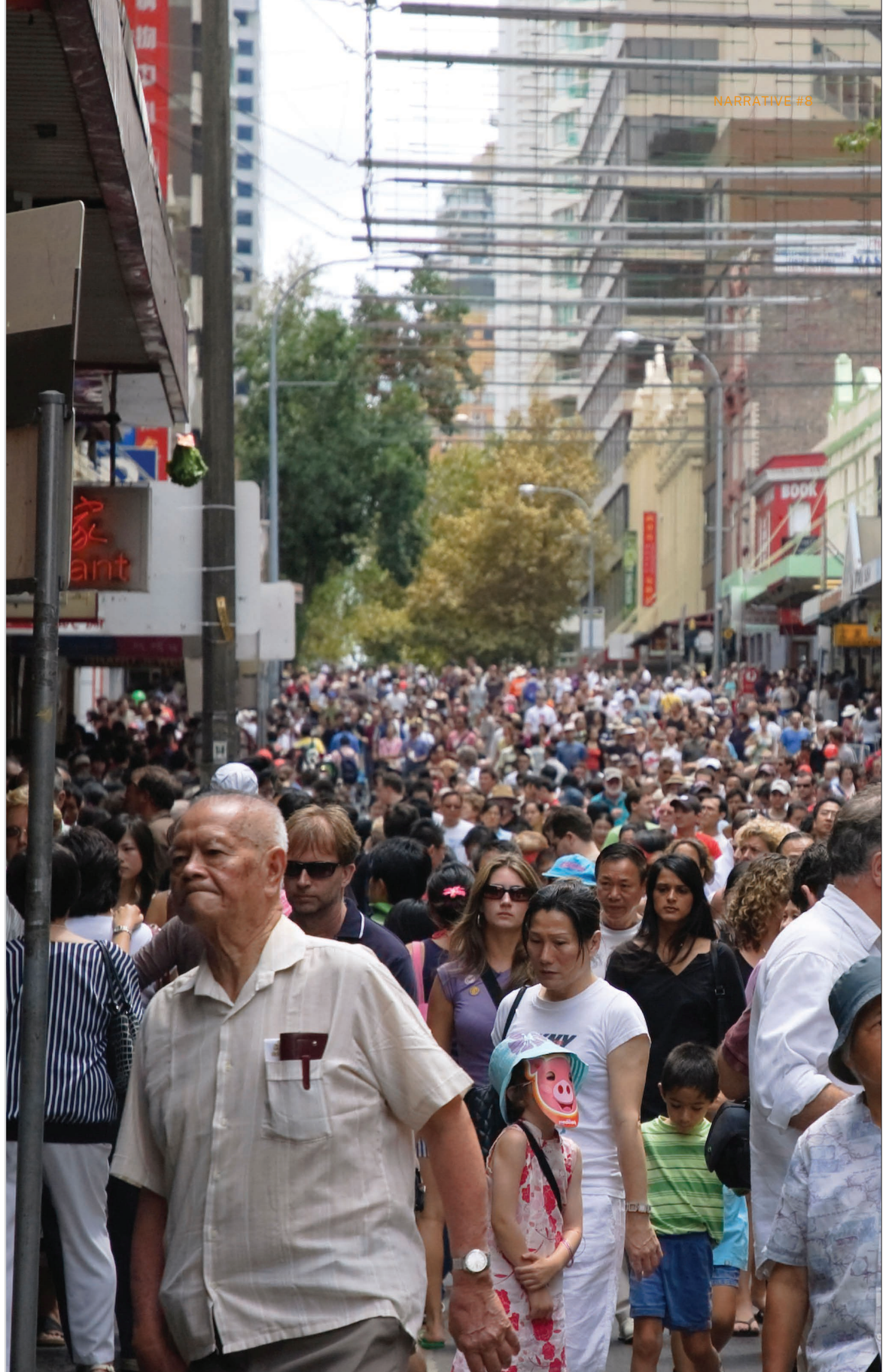
Some legislation designed to address parts of the royal commission's list of reforms has passed or is due to pass the federal parliament, but voices within consumer and industry groups are concerned the effort so far risks squandering the once-in-a-generation chance at renewal provided by the commission.

Yet for all its sweeping lines of inquiry, the final report of the aged care Royal Commission did not categorically address the implications of its findings for diversity, according to the Federation of Ethnic Communities Councils of Australia (FECCA).

FECCA's formal response to the Royal Commission said that while it took "a landmark approach" in allowing culturally and linguistically diverse people to make submissions in their preferred language, the final report failed to outline "how the new system would meet the needs of culturally and linguistically diverse older people."

"FECCA, together with its members and stakeholders, is concerned that the recommendations of the Royal Commission missed a critical opportunity to embed systemic reforms that will improve aged care for culturally and linguistically diverse older people." While acknowledging that the inquiry tried to deal with such matters under the "guise of an individualised approach," FECCA argued that this approach would do nothing to address structural inequity in the system.

Australia's migrant and culturally diverse community, in absolute numbers, has never been bigger. They are ageing, too. If nothing else, mathematics points to a looming policy problem.



The numbers:

How culturally diverse Australians are changing the nature of aged-care services

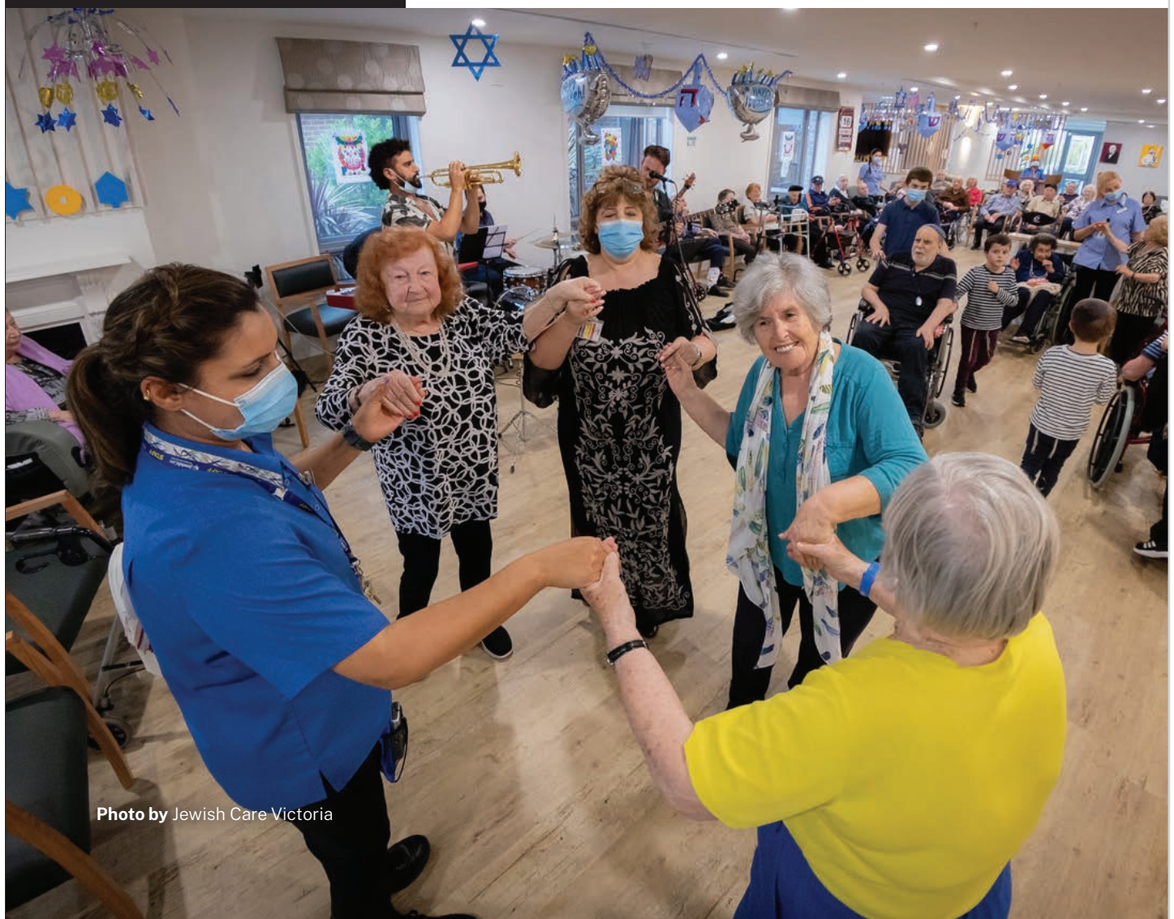


Photo by Jewish Care Victoria

In 2017 Ljubica Petrov and her team at the Melbourne-based Centre for Cultural Diversity in Ageing sought to identify the cohort of culturally and linguistically diverse people accessing residential aged care services across the country.

In a paper for the journal, Australian Health Review, Petrov, Catherine Joyce and Tonina Gucciardo-Masci found that more than 170,000 people lived in residential aged care facilities in Australia. More than 30,000, representing almost one in five (18.3 per cent) residents, were born in a non-English-speaking country. The proportions varied from 6.9 per cent in Tasmania to 23.9 per cent in Victoria, with the vast majority living in Victoria and NSW.

About 16,000 residents of nursing homes indicated that their preferred language was not English. Some of these were Indigenous people, particularly in the Northern Territory, but most were from migrant communities in NSW and Victoria. Unsurprisingly, most came from migrant groups who have been in Australia for many years.

Case study 1: Jewish Care and the aged care needs of Melbourne's Jewish communities

When Jewish Care was established, more than a century and a half ago, there were only about 200 Jewish people in Australia. The organisation started as a group of volunteers who wanted to do something to look after those who were less fortunate. Since then, Jewish Care programs have expanded into the aged care, family, social service and disability sectors. It is now the largest provider of aged care services for Australia's Jewish community.

The breadth of aged care services the organisation provides is significant. They include active living centres, where people can access allied health services like

occupational therapy, dentistry and physiotherapy, along with social events and programs. These centres cater for those in the community who are living independently but need a little bit more in terms of extra health care and support, along with a regular social outlet.

A significant part of the services Jewish Care provides is a program of home care packages to support people to live their final years in their own home.

Not everyone comes into residential aged care, says Jewish Care CEO, Bill Appleby:

"Supporting dying at home with dignity and in familiar surroundings of a person's home is a wonderful outcome if it can be supported. Every individual is unique."

Although the community is diverse religiously, culturally and ethnically, most people prefer to remain as long as possible in their own home. Packages are based either on Commonwealth or external funding. The first generally allows 12 to 15 hours of in-home care per week, which means family members still have to provide significant support. In many Jewish families, the person who takes on this role is often the daughter of the elderly community member or the son's wife. For Holocaust survivors, the Material Claims Conference in New York provides funding (on behalf of the German and Austrian governments, and much greater than what is available under Australian federal funding) to allow them to be cared for at home. A small number in the community have the private means to fund home care, paying for the support and medical services their loved one requires, even to the extent of 24 hour-a-day care.

The final tier of Jewish Care's aged care offerings are its three residential facilities. Rather than 'strange places behind a dark fence,' they are based around the 'small house' model favoured by the Aged Care Royal Commission, featuring a smaller number of residents living in a home-like environment. The facilities are designed to support residents to live as independently as possible, with an emphasis on food and amenities being easily accessible, and generous communal space. The residential facilities are located within what Bill affectionately calls "the bagel belt," those suburbs where the majority (76 percent) of the Jewish community of Melbourne live. Most residents enjoy being close to family members, as well as synagogues, kosher food stores and eateries. The location of the residential facilities allows most to receive multiple visitors each day, an expression of the community's focus on being together.

Because of the impact of the Holocaust and the trauma that has transferred from survivors to later generations, Jewish Care tries to employ predominately Jewish staff. Yet since many of its aged care staff are not Jewish, these employees are helped to learn and understand what it means to be Jewish and what its clients require in terms of both practical and intangible support.

As with other religious communities, there are cultural overlays to being Jewish. Jews who come from the former Soviet Union have different food preferences, language requirements and cultural norms to those who grew up in Poland, for instance. Jewish Care is careful to keep these elements in mind, serving familiar recipes from home countries. To meet the language requirements of those who have reverted back to their native tongue the organisation generally uses official interpreters for anything that requires legal or medical consent; however, day to day navigations are usually managed informally by staff with appropriate language skills.

One challenging situation Jewish Care needs to navigate is meeting the religious requirements of its residents. Traditionally, members of a synagogue pay for their membership, yet once a person is in residential care that relationship lapses. As Bill explains, once a person stops paying and goes into residential aged care, "all of a sudden your Rabbi for many years may stop seeing you." Jewish Care has worked hard to ensure its residents continue to receive pastoral outreach from rabbis even once their financial relationship with the synagogue has ended.

As average family size is reducing, Bill believes the residential aged care facilities available for the Jewish community in Melbourne are probably adequate for future needs, yet the need for in-home services is likely to grow:

"Certainly, family size is reducing in the non-orthodox community. In terms of what do we need, we don't need any more residential aged care... I believe there'll be a decline in residential aged care bed needs. So, for us, we have got enough. Obviously, a large percentage of our Holocaust survivors are going to be lost over the next 10 years or so, and we are already seeing that."

Community identity is a very strong element of the Jewish community so Jewish Care's aged care services are provided through this lens. They employ rabbis, observe the highest level of kosher dietary requirements (running both meat and milk kitchens) and celebrate or commemorate all the Jewish high holidays. All these elements of this care represent a significant unfunded cost to the organisation. Providing kosher meals, for instance, is far more expensive from a raw ingredients' perspective.

The shortfall between what the government provides and the organisation's expenses needs to be made up through donations, since there is no extra government provision to support cultural needs. Viability is Jewish Care's greatest challenge, as Bill explains:

"At the end of the day I could be running another aged care company and we'd be getting the same funding for Myrtle as for Esther. Esther comes from a war-torn country. She's a Holocaust survivor. She has a whole lot of psychosocial needs because of that experience that are very complex, but I'm getting the same amount of money from the government to support those needs."

Italian speakers were the largest group, followed by Greek, Cantonese, Croatian, Polish and Russian. These six languages cover about 90 per cent of all non-English speaking nursing home residents. While these residents are generally more likely to have the opportunity of speaking with a staff member who knows their language, others, particularly those from so-called new migrant communities, risk facing deep isolation.

About one in four people (26.1 per cent) living in Victorian residential facilities whose preferred language is not English is the only resident within the facility who speaks that language, Petrov and her colleagues write in their paper. A further 10 per cent are in a facility where only one other resident speaks their preferred language.

The paper focused on nursing homes, yet these institutional settings are increasingly an artefact of a different time and thinking. Things are changing, and those from culturally diverse backgrounds are leading the change.

Although they represent 23.3 per cent of the 'target aged care population', older Australians from migrant communities are not heading into nursing homes at nearly the same rate as other Australians. Petrov's study indicates that just 18.3 per cent of aged care residents come from minority backgrounds. A more recent figure from the Productivity Commission's Report on Government Services show that the proportion rose 19.3 per cent in 2019-20, but the gap between migrant Australians and all Australians remains significant.

However, the former group is over-represented among the relatively new system of Home Care packages. Under this initiative, introduced as part of Labor's 2012 aged care reforms, government funds are made available across four support package levels (1 to 4 in order of increasing value) to allow people to receive care where they live.

The idea is simple, arising from the Productivity Commission's 2011 report into aged care: bring support to people where they are — where they would prefer to be — in their own homes. Over four package levels increasing in value as a person's assessed needs increase, the federal government will pay between $9026 and $52,377 each year directly to an older person who can use this funding to purchase a range of supports such as nursing care or domestic assistance.

There are capped co-contributions providers can charge pensioners of between $3606 and $4022 each year (worked out as a basic daily fee) but this cost is added to the package and can be used to buy additional support. Providers might not charge it at all. For part-pensioners or any single person earning more than $28,472 in any year there is a separate income-tested care fee which will be charged, worked out based on a person's individual income. These can range from up to $5758 per year for part pensioners earning between $28,472 and $54,990 or up to $11,516 annually for those earning more.

One of the key principles behind home care funding is that the increased support, above that offered by the simpler Commonwealth Home Support Programme, would allow people to stay in their own homes as they age, reducing the influx into the far more expensive option of nursing homes which most older Australians would never choose for themselves in any case.

Now, more than 100,000 Australians receive home care package services, according to Commonwealth Government figures. People from migrant backgrounds make up 27.7 per cent of those receiving the low-level packages, and 28.7 per cent among the highest packages.

It is a similar story for Aboriginal and Torres Strait Islander people. They comprise 3.5 per cent of the target aged care population but just 1 per cent of nursing home residents. Among all Australians with level one and two home care packages, however, the proportion of Indigenous people rises to 4 per cent. (Since First Peoples have far shorter life expectancies than do non-Indigenous Australians. Aged care policy universally counts Indigenous people as being eligible for services from the age of 50. Everyone else is eligible at the age of 65.)

In the cold lingo of government affairs, having too few 'customers' in a quasi-market to justify a service such as aged care is called a 'thin market'.

But as FECCA's Mary Ann Geronimo is at pains to point out, this is simply not true.

"This concept of multicultural care being a thin market is really problematic," she says.

What such a label really signifies is that people from backgrounds that do not fit the mainstream Australian 'type' are not worth the investment. Even if institutions fail to heed the call for an aged care system with human rights at its core, the data reveals that there is a *market*. It's a big one. And it needs the investment.

Case study 2: AMAN Aged Care and meeting the needs of aging Muslim Australians

About 600,000 Australians — about 2.6 percent of the population — identify as Muslim. While Muslims are younger, on average, than the broader Australian population, they are increasingly concerned with how to meet the needs of their elders, particularly those who immigrated to Australia in the post-war migration boom of the 1950s and who took refuge in Australia after the Lebanese civil war from 1975.

Islam is a lived religion, which means its practice impacts the daily lives of those who follow it. Some acts of worship, such as prayer and mosque attendance (if possible), must be performed regularly. Rules govern the consumption of food and drink, and social norms influence how interaction with non-family members takes place. For many Muslims entering their last years, these lived aspects of their religious life provide important meaning and structure, and become even more important in their final years. Many Muslim Australians are therefore seeking aged care facilities or services that can help them to meet their religious requirements, or at least be cognizant of them.

The word *aman*, which in Arabic means safety or peace of mind, governs the ethos of AMAN Aged Care. Associated with the Lebanese Muslim Association and located in Lakemba, Sydney, AMAN Aged Care has been established to provide culturally appropriate aged care services for local Muslims aged 65 and over. It will run a 112-place residential aged care facility, as well as in-home care services. While both are only in the planning stage, Ahmad Malas, AMAN's General Manager, has no doubt there is significant demand for the services AMAN will provide.

Traditionally, Muslim communities have objected to outsourcing aged care beyond the immediate family. Islam requires Muslims to care for each other, no more so than when grown children have ageing parents. The Qur'an instructs:

Thy Lord hath decreed that ye worship none but Him, and that ye be kind to parents. Whether one or both of them attain old age in thy life, say not to them a word of contempt, nor repel them, but address them in terms of honour. And, out of kindness, lower to them the wing of humility, and say: "My Lord! bestow on them

thy Mercy even as they cherished me in childhood." (Q 17: 23-24).

Caring for elderly family members is seen as an act of worship that should be embraced unreservedly and that is rewarded in the afterlife. Placing elderly parents into residential care therefore carries a stigma and widely is seen as a failing to fulfil familial and Islamic obligations. Fear of community backlash is so significant that many families actively take steps to hide the fact they have engaged such services.

As Ahmad explains: "Some people, what they do because of the stigma, is that they hide the identity of that family member being in care.

As a community member, I know prominent individuals who have put their parents in a facility. They hide it because of fear of the shame and poignant accusations around it.

The son would request with management to ensure that the parent of his is not mentioned in conversation that this person, the son of so-and-so, is actually in our facility. People would take it as sending the wrong message [when] the children should be caring for their parents."

Yet for Muslims in Australia, many of whom are struggling to meet work and cost-of-living demands while balancing their own family obligations, the pressure of caring for aging parents is significant. As Ahmad says:

"One of the things that we're seeing in the community is that there are divorces because of having parents at home. The expectation in the Muslim community generally is that the elder son takes care of the parents ... and then that's generally offloaded to the daughter-in-law or the wife. And obviously, because of financial demands, the couple would often need to work. There are so many commitments that it is a challenge to just leave everything and care for your parents..."

The cost of this caregiving is even higher when coupled with conditions like dementia. Many Muslim families are therefore opting to use residential facilities that can provide a qualified level of care.

Ahmad and others involved in the AMAN aged care project are working to bring the community on the journey with them. They propose that it is actually doing elders, especially those who need extensive care, a disservice not to provide them with the care they need. Given the different dynamics that Muslim families in Australia face (especially in comparison to home countries), it may be more appropriate to engage an aged care service, instead of struggling with the challenges of providing high-level care within the family.

For Muslim families considering residential aged care for their parents, certain things will make the transition easier. While there are different levels of piety in the community—from those who are more nominal to those who are quite strict in their adherence to the religion—families are generally looking for halal meals (made according to Islamic food laws), on-site prayer facilities and proximity to the local mosque so that families can attend Friday services together. For those on the stricter side, the housing of men and women in separate wings and gender appropriate carers (male carers for men, women carers for women) is a requirement, as is the veiling and modest dress of female staff. Many families also seek facilities where staff are proficient in their first language, whether Arabic, Turkish, Persian or Urdu. AMAN will also model their rooms on the dome-like look of the local mosque, which Ahmad believes will help to create an environment of spiritual reflection and contemplation in the facility.

A challenge that Muslim aged care providers face is how to cater to the diversity of the community. Muslim Australians come from as many as 120 different ethnic backgrounds, which means it is difficult for providers to take into account religious as well as cultural preferences, as Ahmed explains:

"How do you provide something that's culturally appropriate knowing that your clients are from a very diverse background? What is good for someone who is Lebanese is very different to what someone from the subcontinent like Bangladesh or Pakistani might want. For a Lebanese Muslim, even a Lebanese Christian might be closer in terms of traditions and practices to a Muslim from Bangladesh."

While the religious aspects of the provision of aged care might be relatively clear, the cultural aspects provide another layer to the meeting of peoples' needs. Muslims from the Middle East and the subcontinent may share the five central tenets of Islam, yet their cultural experiences of food, traditions of celebration and dress, not to mention spoken language, are quite different. Sometimes, as Ahmad notes, both the cultural and religious aspects of life and practice are blurred together, which makes it difficult to distinguish what's what. This makes service provision a little more complicated.

Ahmad therefore sees AMAN's role as "catering to as much of those cultural aspects as we possibly can". While it will be challenging, his team's desire is to see people as comfortable in the later years of their life as they can possibly be.

A brief recent history of the aged care sector

Before John Howard became Prime Minister in 1996, the Federal Government struggled to manage the increasing cost and difficulty of providing some form of nursing or hostel care to older Australians. Many governments had sought to change the status quo, but it was Howard who sensed that a more permanent solution could be found.

All he needed was to give the private sector a reason to invest in aged care and, in so doing, shoulder a large part of the taxpayer burden. Not all of it, mind you. The 1997 reforms, followed quickly by the removal in 1998 of the requirements for a Registered Nurse to always be located in a facility, paved the way for a gold rush of private aged care companies.

Yet the one thing Howard really wanted to give these providers was too politically risky and had to be abandoned. That was his promise to introduce nursing home bonds — lump sum payments that could be used by providers to build new homes or invest, accruing substantial returns.

It was a Labor Government that ended up introducing these bonds, in 2012, although the then Minister for Mental Health and Ageing, Mark Butler, says he was faced with a prickly decision. In return for introducing the bonds he had sought other concessions from the industry, such as mandatory staffing qualifications and pay rises, which he secured before Labor was turfed from office.

This history is the context for the sector we have today.

Although the number of private aged care providers is falling, this figure hides the nature of the change. These for-profit providers have increased their ownership of operational aged care places (nursing home beds) from 35 per cent in 2011 to 41 per cent last year. Over the same period, the market share of religious providers fell from 27 per cent to 23 per cent. Not-for-profits that provide care to people in a specific location or from a particular ethnic group (known as community-based care providers) have also shrunk from 13.7 per cent of places to 13.1 per cent. The charitable sector grew its share by just 1 percentage point, to 18.7 per cent over the decade.

Home care packages became the next big thing in 2017 when Labor's reforms reached maturity under the Coalition, and in just three years, private providers more than doubled their share of these supports, to 26 per cent. Over the same period, religious groups' share of the services plummeted from 32 per cent to 26

per cent, while among charitable organisations, home care service offerings have fallen from 32 per cent to just below 27 per cent.

These changes raise concerns about quality: evidence before the Royal Commission from two different studies shows that small government services provide the best level of care in nursing homes, for example, while large private facilities provide the worst. There is another problem, too.

The aged care system is a government-funded and regulated quasi-market, yet its key functions are outsourced to organisations that are neither run nor effectively monitored by government. Even if a free market eventually meets consumer demand, as some economists suggest they invariably do, how can a hybrid model subject to state funding caps ever achieve this?

Monash University Professor Joseph Ibrahim, a specialist in geriatric medicine, told the Royal Commission that the current model was his core concern and this was most evident in Residential Aged Care Services (RACS).

Ibrahim said in his witness statement that while the services were promoted in policy and regulation as being a "person's home," the reality and practice did not quite match. "It is unrealistic to consider that RACSs could be all things to all people and able to deliver the diversity and uniqueness of each person's household when they become a resident," he said.

Ibrahim said that both diversity in the resident population and the facility profile — including the number and type of residents, geographic location, physical environment and staffing — made it hard to design a set of objective, universally applicable metrics that could measure how well a RACS was a "person's home". While the typical RACS resident was a woman of about 83 years old, with multiple chronic illnesses, including dementia, that picture concealed a multitude of residents, with highly diverse capacities and needs.

Within a year of accommodation bonds becoming legislated, allowing nursing home operators to levy lump sum entry payments on residents when they enter nursing home care, three aged care companies listed on the Australian Stock Exchange. Today, the average Residential Accommodation Deposit (RAD) held by operators is $334,000. Collectively, some $32.2 billion worth of these deposits are held in accounts across the country.

The deposits must be returned, minus any fees and charges, to a person or person's estate when they leave care. Nevertheless, providers are legally allowed — in fact, encouraged — to invest these amounts and use the interest to fund further investments or meet other operating costs.

Around the time these deposits were introduced, growing in value year-on-year, a new Coalition government under Tony Abbott came to power and moved quickly to reduce funding elsewhere in the sector. To do so, it targeted direct care subsidies.

Since 2000, the cost of providing care in nursing homes has risen by 116 per cent. But government subsidies to these outsourced providers have increased by only 70 per cent, according to an analysis performed by the Royal Commission. Much of the gap opened up from 2015 onwards when indexation of the Aged Care Funding Instrument — an unwieldy tool used to determine the basic care payments provided per resident — was frozen, and scoring for complex healthcare domains was changed, resulting in significant funding cuts for the highest care nursing home residents.

The consequence of this compounding attrition was that, by the time the Royal Commission released its final report in early 2021, it formed the view that almost $10 billion had been stripped from the system. Put another way: the annual government budget for aged care services, which was $20 billion in 2018-19, ought to have been $30 billion.

But, as Professor Ibrahim said during evidence to the Royal Commission in May 2019, money is just one part of the equation. Funnelling more of it into the same system with the same identity crises won't change things for the people going into care.

"We keep looking for simplistic solutions for complicated problems, and all we do is make things worse by denying the complexity behind it," he said.

"And we're far more mature — we should be far more mature — than that, but we really want an easy answer. We want to forget about ageing, we want to forget about being old, we want to forget about the difficulties of disability and death. And so we rush to a really simple answer, or we choose the answer that we like from what already exists.

"You can change a person's sense of safety by what is around them and the people around them, if you respect them, and they're able to do things."

Ibrahim pointed out that people differ greatly in how they achieve that sense of safety. Some feel very unsafe when people do not allow them to choose their own path. Others feel safer if others are choosing for them.

"That personal sense is more a sense of security or goes more to my anxiety or wellbeing. It has nothing to do with how a doctor or nurse is providing an injection of a blood thinning agent or an antibiotic."

It is here that the home care revolution has provided the most promise. The Labor Government introduced the home support packages in August 2013, with means-testing introduced

the following year. The new Coalition government pushed ahead with the reforms and introduced the national priority list in early 2017. That was a crucial shift.

For the first time, it was possible to see just how long the waiting list was. The figures were shocking. Within a year, the queue for those who had been assessed as eligible for a home care package but who were waiting to receive one at the level agreed was more than 121,000 people deep.

And that was after the Federal Government released almost 150,000 extra packages across all four levels.

The situation has changed appreciably in the ensuing years, yet 87,000 people are still waiting for a package, according to the most recent data update. The Royal Commission heard evidence that in just two years, 30,000 people died while awaiting access to support for which they had already been approved.

“To get a package at the moment, one of two things has to happen,” Faduma Jama says. “Somebody has to move up to a higher package or somebody else has to die, unfortunately. They have capped it. So a lot of people from our community are just sitting there on the list.”

There is good news, too. The amount of time spent waiting for the highest, Level 4, package — which comes with about $50,000 in annual funding — decreased from almost three years to 28 months in the last financial year. Yet progress is slow and these incremental changes have only happened after billions of dollars in investment in just a few years.

What’s more, there are only 934 approved providers of home care packages, an increase of just six since the beginning of 2019. To Faduma Jama, that presents a serious problem. She says the government wants “to prop up these large in-home care providers and as soon as you have too many people being managed by the one organisation — I’m sorry, but quality suffers. Because there is no choice in the market, where is this person meant to go?”

There is a tremendous opportunity, however, if an overhaul of the system can introduce a concept known as the dignity of risk. It’s a common concept in disability and aged care literature, and one Professor Ibrahim spoke of eloquently at the Royal Commission. To have this dignity is to be fully human: allowed, indeed encouraged, to make choices for yourself within the bounds of the law even when these decisions carry potentially harmful consequences. The key is the choice.

To be cartoonishly simple about it, an 85-year-old woman living in residential aged care should be allowed to go skydiving, if she would like. Or eat steak, or dessert; or to make decisions about care that may invite strangers into the home.

Part of achieving this dignity of risk, then, must extend to providers of home care services from under-represented communities. The demand is there, but entry for workers and providers can be unnecessarily burdensome. Jama says the Somali community is ready and able to do this home care work, but the approval process is bureaucratic and overseen by people who don’t quite understand the concept of belonging.

The problem is that culturally representative providers are rare, Jama says. She notes that the system has changed: whereas providers once held home package funds and it was difficult for the client to move around, now the money goes to the person who needs the care to spend as they wish.

“That’s great, but now the government needs to meet that demand and allow more providers who can actually give that culturally competent care,” Jama says. “I know plenty of organisations led by nurses who have been knocked back by the regulator for ridiculous reasons. Yet another organisation led by a guy with a marketing degree was totally fine.

“The problem is, the approvals come out of Canberra. They have no idea what on the ground work is like and what is needed.”

There is a distance here, between the reality of lives on the ground and those who make decisions for and about them from the centralised positions of power in Australia. This gulf begins with language.

The words to say it:

Why language matters to the elderly

Angelos Angeli, who is of Greek-Cyprian descent, arrived in Australia as a toddler with his parents after the end of World War II. He is an only child and, since the death of his father, his mother's only carer.

At first, Mrs Angeli was offered only a Level 2 home care package, despite being assessed as needing a Level 4, the highest offering. Even so, the support changed her life. It offered her "some cleaning around the house, maintenance of the property, as well as allowing [her] to go out," her son told the Royal Commission.

Mrs Angeli liked to visit her husband's grave, and she needed support to attend the GP. Support workers would help her do both, Angelos said. Critically, the provider had a Greek-speaking worker at that time. That worker would accompany Mrs Angeli when she shopped, which her son could not do because of limited time. "They allowed her to go to some place — a specific shop — and buy whatever she needed."

More than anything else, it was this sense of connection that mattered. Mrs Angeli spoke very little English and found her world shrinking as she grew older. Then the Greek-speaking home support worker left the organisation for personal reasons, which was a big blow. It's also extremely common.

Angelos said that when a new worker attended his mother's home, "they couldn't communicate, or the communication was very limited. It probably made her further socially isolated ... and lonely. It has gotten worse because unfortunately a lot of her friends have become unwell, and so they've been put in homes or they've passed. So, she has become more and more socially isolated."

In one good turn of events, the local council introduced a bus service to bring elderly Greek residents together every Monday, taking them for coffee or games. On that day "she gets out and meets people, but the rest of the time until the weekends, she is effectively home alone, or the nurses attend, but ...only for a short amount of time," Angelos told the Royal Commission.

Language arrived in the evolutionary blink of an eye. While scholars have long argued over its precise function there is no doubt that it gives our lives texture and meaning. In fact, the way a culture or speakers of one language see the world is fundamentally changed by the lexicon of the mind.

Cognitive scientist Lera Boroditsky, a world expert on the way language shapes our thinking, has studied a community of First Peoples on Queensland's Cape York Peninsula and found something truly astounding.

In Pormpuraaw, children as young as five can instantly tell you which way is north, south, east or west. Of course, many English speakers could do this, too, but they must think about it.

For this community, knowing where you are on country is critical and in the Kuuk Thaayorre language, there is no traditional hello. Instead, they greet each other by saying "Where are you going"? An appropriate response, according to Boroditsky, is: "A long way to the south, southwest."

Previous research has noted that speakers do not use left or right, up or down as a way of orienting themselves outside of travel. For example, a speaker might ask someone to move a cup over to the north, northwest a little bit. Or they might say 'the boy standing to the south of Mary is my brother'.

When asked to arrange events in order from the past to the future, English-speakers tend to do so from left to right. In Mandarin, for example, speakers will tend to place events in order of time flowing from top to bottom.

The past is above, the future below. Residents of Pormpuraaw have a completely novel way of dealing with the flow of time. When asked to place a set of cards depicting a person ageing in order from baby to old age, they do it in the direction the sun travels, east to west. But this is entirely dependent on the direction they are facing when they are asked. So, they will order the cards from left to right when facing south, right to left if facing north, toward their own body when facing east and away from their body when facing west.

Translation can bridge some of the gap between speakers of different tongues, but alone it is not enough. In aged care, or any other service for that matter, understanding this is vital.

Meeting people where they are — in their own home or language, should they desire or need it — is not a mere matter of utilitarian communication. It is an instrument of belonging and of love.

Pine Lodge:

Why it is vital to play on "residents' turf"

Some services and nursing homes — almost always led by their own communities — have written this idea into the code of how they operate.

The Pine Lodge Home for the Aged in Rocklea, a suburb in Brisbane's southwest, began life as a Russian diaspora project in the late 1960s. The home was built, and rebuilt, on land owned by the Russian Orthodox Church and dedicated to the Blessed Virgin of Vladimir. Today it is a thriving nursing home built from within a community, not outside it.

A registered nurse who worked at the facility, who cannot be named for professional reasons, said it was her favourite place to work across her career. "It is co-located with a Russian Orthodox church, so family used to pop over before or after church," the nurse says. It was a single site, run by a very involved board that would drop in frequently, and all of whom were from the local Russian Orthodox community. The facility manager did not have a clinical background but was a respected leader in the Russian community.

This demarcation improved the service. Clinical matters were left to the supervision of clinicians but all other staff, including personal care attendants, were almost exclusively Russian or from the former Soviet Union, the nurse says. While most registered nurses were Anglo-Celtic Australians, "pretty much everyone else was Russian, and the chatter around the facility was all in Russian. That was the default."

The nurse says that if she needed to be involved, a personal care attendant or another staff member would translate into English. The facility even had an informal arrangement with the Queensland Ambulance Service that sent Russian-speaking paramedics to take residents to hospital. The nurse says there was no command-and-control structure. On any day, staff felt like they were working on "residents' turf".

"They had a swanky, big, copper coffee machine, Russian ladies working in the kitchen making traditional, delicious dishes like borscht and an oatmeal dish for breakfast served with butter. It really felt like…the language and culture and day-to-day life was as Russian as it could be in southwest Brisbane."

The aged care regulator, which has gone through a few iterations in the past decade, is a capricious operation. It can miss things, or disproportionately penalise relatively minor things, but even so the

accreditation audit reports make useful reading. Pine Lodge has never had a notice of non-compliance issued against it. The service has passed every audit since 2009 with full marks.

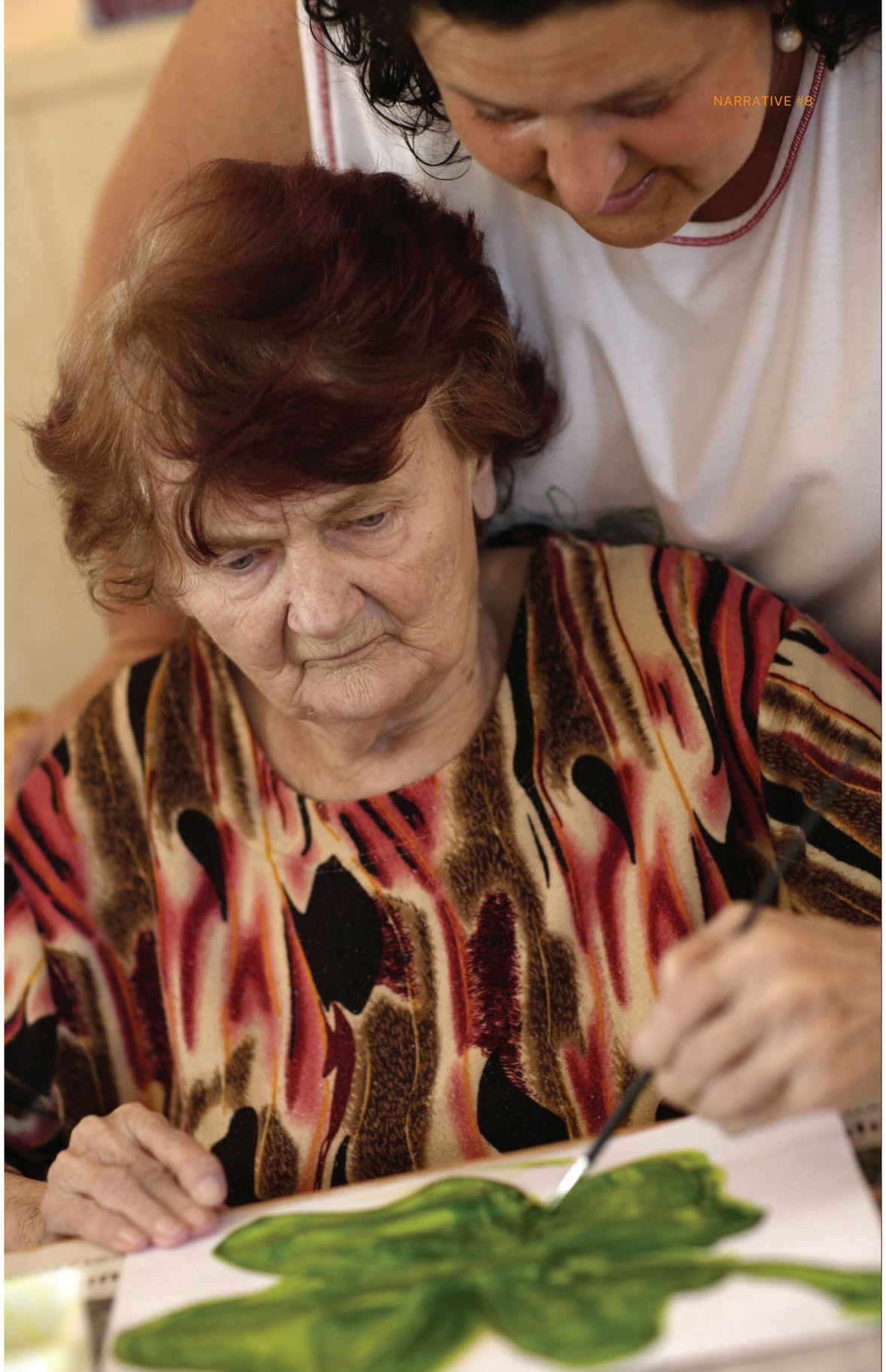
Auditors noted that after one trip in Brisbane, where residents performed karaoke, they requested it be added as an activity in the nursing home. “As a result, the service has purchased karaoke equipment, gold microphones and karaoke is now a regular activity,” the January 2019 assessment report says. “Care recipients and staff said this activity is very popular and well attended.” Residents also requested a New Year’s Eve event, at which “celebrations continued until after midnight.”

It is no fluke that Pine Lodge consistently does well, even in a funding environment characterised by cuts and erosion. The facility has a mission. In order to recruit and retain registered nurses with an interest in aged and multicultural care, Pine Lodge has developed a transition program for newly graduated registered nurses.

The 2019 audit says participants in the program are rostered to work Monday to Friday, morning shifts only, and are mentored by experienced registered nurses whilst they complete a suite of competencies developed by the service. Once completed, they are rostered across shifts and remain supported as new graduates. Management and staff told auditors the program had substantially improved the recruitment and retainment of registered nurses.

Beyond these innovative programs, Pine Lodge’s multidisciplinary approach seeks to address the physical, psychological, emotional, cultural and spiritual support required by care recipients and their representatives, the audit found. A detailed intake assessment records the needs and desires of each resident, and adds them to care plans that are updated and used as a guide when staff attend to people in the home.

Good communication and partnership are essential for giving priority to the wishes of residents. Some organisations understand this point better than others.



The rewards and risks of an aged care workforce reliant on immigration

Fronditha Care, which comprises four aged-care facilities spread across Melbourne's suburbs, defines itself as "one of a few organisations within Australia that has entered into a special agreement with the Federal Government in order to provide culturally appropriate care to Australians with a Greek cultural background."

When the service signed its second labour agreement with the Commonwealth in 2018, it opened the door to bringing in more Greek-speaking, personal care workers into Australia under the temporary skills shortage visa subclass 482.

Although the labour agreement stream of this visa has strict conditions — the time limit is four years and candidates can only work for the one employer — the service is able to sponsor those on its labour agreement visas for permanent residency. Staff who joined Fronditha under the first Labour Agreement between 2015 and 2018 will be able to apply for permanent residency once they complete their four years of service during the term of the second agreement.

Minor changes to these agreements in March 2019 made it easier for aged care providers serving multicultural communities to bring in workers. The need for these changes stems in part from the fact "a number of occupations in shortage such as Nursing Support Worker and Personal Care Assistant are not eligible for skilled migration through the mainstream visa program," according to the Fronditha website.

The Department of Home Affairs told the Royal Commission that new concessions offered to aged care operators under the labour agreement relaxed the age requirements for visa workers (they could be up to 55-years-old instead of having to be under 45) and loosened English proficiency demands.

Yet Covid-19 has upended these arrangements. Almost two years into the pandemic, prolonged international border closures continue to distort the economic and immigration outcomes of countries around the world. Varying global vaccination rates pose ongoing challenges as Australia slowly contemplates reopening.

In the middle of 2021, the Department of Employment established an "inter-departmental workforce taskforce" and set about solving the coronavirus-induced employee shortage. The taskforce includes input from senior bureaucrats in the Departments of Health and Home Affairs, for example, with the Prime Minister Scott Morrison providing key oversight. The work is mostly secret, although some details have been provided for this Narrative.

One huge problem this government working group has examined is the growing demand for aged and disability workers post-Covid. The demand was already astronomical before the SARS-Cov-2 virus made its way into human hosts. Today, supply is nowhere near enough to serve a fully functioning National Disability Insurance Scheme or a dramatically overhauled aged care system with NDIS-like home care packages at its core.

Public service advice provided to NSW Premier Dominic Perrottet and reported on in *The Australian Financial Review* in October urged the new Premier to lobby for a dramatic immigration surge similar to that seen after World War II. Such an 'aggressive resumption' could double pre-pandemic immigration levels to bring in two million skilled migrants over five years.

Former Department of Immigration Deputy Secretary Abul Rizvi says it is unquestionable that Australia will need more immigrant aged care workers as Australia's population ages, but he urges the government not to view this policy in isolation.

"It is really important that what we do in this space in terms of immigration dovetails with the multitude of other issues that are swirling around in aged care following the Royal Commission," Rizvi says. "Increasing immigration as a standalone solution would be a serious mistake."

Rizvi argues that countries such as Japan and Germany have already made this mistake. "They basically picked up low wage workers from a range of countries who had minimal relevant language skills and plonked them with employers who are accustomed to cutting corners and minimising costs in order to deliver often quite poor services to older people," he says.

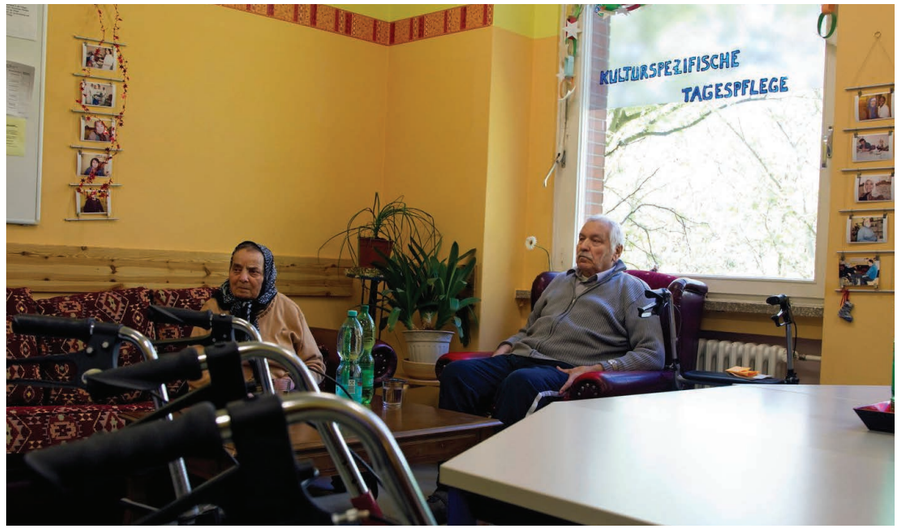
"Now that might sound a bit like Australia and surprise, surprise, private aged care providers in Japan and Germany etcetera behave in much the same way."

Rizvi, now a special adviser to communications firm Michelsen Alexander, says labour agreements between employers and the Australian government are a good idea but "quite boutique" and therefore unable to meet the need for future workers.

Rizvi worries that the government will replicate in the aged care sector the problem he believes it has created with its new agriculture visa. He defines that problem as finding workers to fill low-paid, low-skilled jobs that are highly vulnerable to exploitation, wage theft and abuse. "Using immigration to fill those gaps is exactly the wrong thing to do."

Rizvi thinks that while immigration will be crucial to addressing the needs of the aged care workforce, "the prospects of stuffing this up are enormous." He identifies one critical measure that could be taken to alter the power imbalance: the Commonwealth should insist that any labour agreement or visa mechanism sets a floor for the salaries that employers will pay staff, and attaches strong penalties for those who fail to comply.

Finding workers for an already strained sector is a priority, made even more urgent by the coronavirus pandemic. Yet the Federal Government has not increased the minimum salary level for any employer-sponsored temporary entry visa in any industry since 2013. Rizvi says: "If you persist with the insecure nature of work in this space, you're just asking for the troubles to get worse and worse, even if COVID isn't around."



Another way?

In Sydney's northwest suburb of Marayong, Holy Family Services, a Catholic welfare organisation, operates a nursing home, retirement village, school and long day care centre for young children on the one site.

The Sisters of the Holy Family of Nazareth started the service in the 1950s to provide care and language teaching for displaced Polish migrant families in the area. As the decades wore on, and the community grew older, the nursing home was added in 1990.

Holy Family Services CEO Alexandra Davis says that integrating children from the school and childcare centre with elderly residents has been critical to the success of the organisation. Over a 10-week program at the school, children do activities such as sharing and telling stories with the residents, based on a curriculum written by Davis and teachers.

Even between COVID lockdowns, visitors to aged care homes were sometimes banned under public health orders. Davis had an imperfect solution. "The children still come over and do window visits," she says. "They did videos, too, that they sent to us so the residents could watch them. The smiles on their [residents'] faces were amazing; it was just really incredible."

Student visits to elderly residents had taken place for more than 10 years before COVID struck but they seemed to take on an especially vital air during the lonely months when the residents saw only staff. Holy Family Services Leisure and Lifestyle Coordinator Izabela Gendera-Bres told *Catholic Outlook* that some residents were settled and calmed by the window visits. One older gentleman, a widow with no children, began to cry.

"It's wonderful therapy for them," Gendera-Bres said. "I think the Pope said it very beautifully. Children are kind of angels — interacting with them, we can easily move into their world, which is full of peace, happiness, positivity, joy and fun."

Although the service is set up for Polish people, and half the staff speak Polish, it is not exclusive. There are Maltese and Italian residents, and a handful of others from different cultures. "Some of our Filipino staff can speak Polish better than some of the Polish people because they have been here for so long," Davis says with a laugh.

In addition to specialising in culturally safe care, the nursing home — also known as Brother Albert's Home — has developed expertise in delivering "behavioural support programs for elders with dementia."

An audit conducted by the (now superseded) Australian Aged Care Quality Agency praised the nursing home's decision to allow registered nurses to upskill "to become champions in one particular field, such as advanced care planning, dementia care, wound care or palliative care."

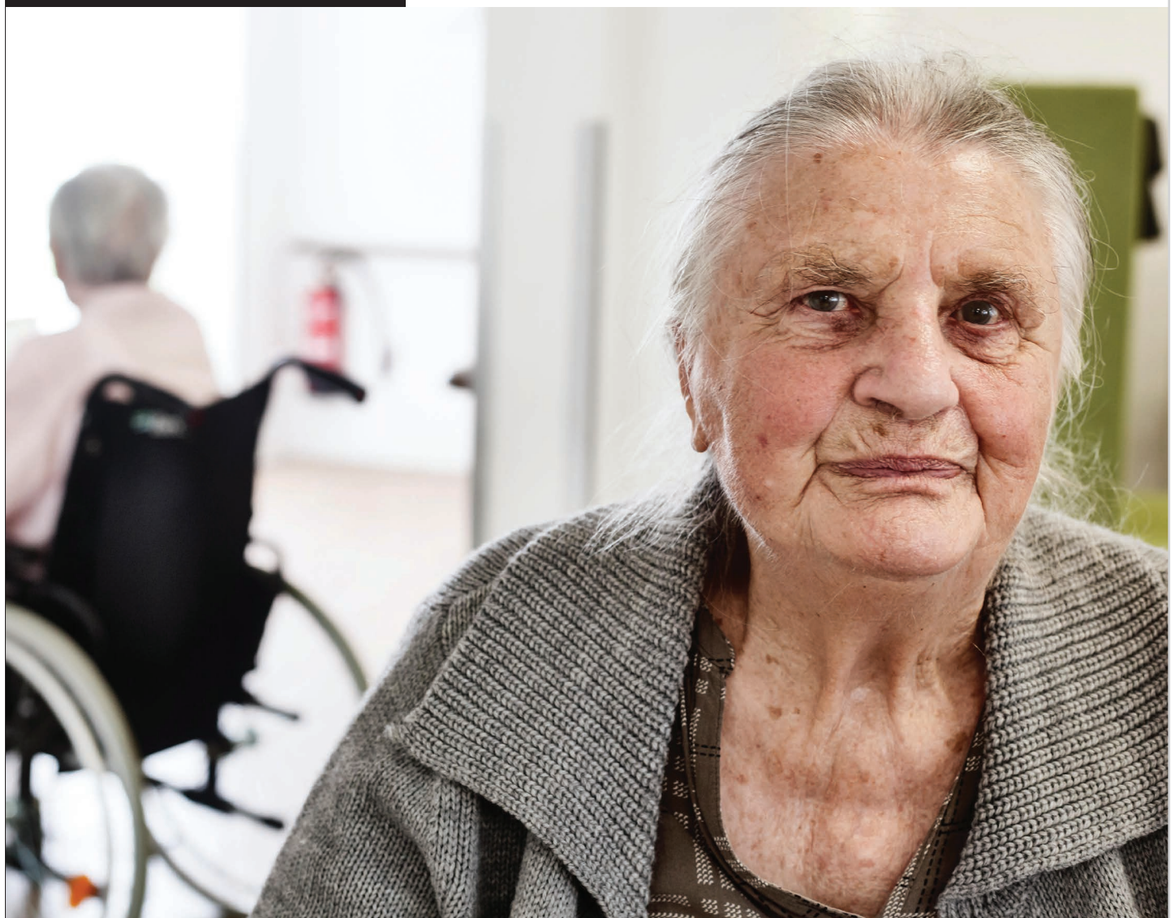
Under the new model, registered nurses at the home are supported by the service to choose a preferred field of study, and after undertaking a suitable course, they bring their new knowledge back to the facility to share with other staff. Management said that this approach ensured residents received best practice models of care, and the auditors agreed.

The home practises a "minimal restraint policy", the audit says, which is an indicator that staff are able to manage challenging or difficult behaviours with care and attention. "The home currently has no care recipients requiring restraint," the audit found.

Registered nurses play a crucial role in ensuring high quality care, as the Brother Albert's Home example shows. However, between 2003 and 2016, the share of the residential direct care workforce held by registered nurses fell from 21 per cent to 15 per cent, according to the final report of the Royal Commission. Over the same period, the proportion of enrolled nurses fell from 13 per cent to 10 per cent, and the proportion of direct care employees working in allied health roles also fell. Conversely, the proportion of the residential direct care workforce who were personal care workers rose from around 58 per cent to around 70 per cent. Personal carers are a critical part of any aged care workforce but they are also the lowest paid and least qualified. As care needs have grown and funding has contracted, these employees have often been given the responsibility previously attached to qualified nurses.

The innovations underway at Brother Albert's Home are worthy of study, since it is essential to understand the role of dementia if we are going to improve the lives of all Australians, including those from diverse backgrounds, who are receiving aged care.

The bridge between dementia and love



Half of all residents in Australian residential aged care facilities have a diagnosis of dementia, and 90 per cent of all residents have some degree of cognitive impairment, according to the submission of the Australian Pain Society to the Royal Commission.

Over the next three decades, the proportion of people from diverse cultural backgrounds in aged care is projected to grow by 200 per cent, from about 40,000 people today to 160,000. The current data for diverse aged care recipients are patchy and this is a conservative estimate. Whatever the size of the increase, the cohort of people with dementia for whom English is a second language will also rise.

This year the Federal Government funded the National Ageing Research Institute to develop specialist dementia training for interpreters and translators who help to perform cognitive assessments for people from culturally and linguistically diverse backgrounds. The Institute's Director of Social Gerontology, Associate Professor Bianca Brijnath, says that part of the drive for change has come from interpreters themselves, who increasingly recognise the need for specialist training in dementia.

Brijnath says that interpreters are working with growing numbers of people with dementia but research has found that these workers have wildly different experiences and understanding of the disease. As a result, inconsistencies in interpreting have reduced the validity of cognitive assessments, lowered clinician and patient satisfaction, and overburdened health services.

Relying on interpreters with limited knowledge of dementia in their own language can unintentionally influence these assessments, and, therefore, the support that is provided as a result.

The Institute's CALD Dementia Research Action Plan finds that culturally diverse Australians are diagnosed with dementia later than other Australians, and that awareness of dementia is low in some minority communities.

"Many people from culturally diverse backgrounds experience difficulty finding culturally-relevant aged care services," the plan states. "Understanding cultural differences in approaches to dementia, the role of ethnicity or migration experience in disease risk, and attitudes towards

care, are therefore important elements of Australia's research program to address the challenges that dementia presents for all of Australia's ageing population."

Researchers have long observed links between "severe behaviour" responses among people living with dementia and the quality of care around them. Research shows that the underlying cause of difficult behaviour, such as "calling out" or being aggressive to other residents or staff, is in many cases not dementia but the experience of pain and the inability to communicate it to support workers.

The Australian Pain Society's submission found that many people with dementia "are unable to communicate or express their pain due to major cognitive or communicative disabilities…leaving it frequently unrecognised or undiagnosed." This is a particular challenge for people whose first language is not English, Brijnath explains.

While many Australians from culturally diverse backgrounds speak English, a common symptom of dementia is aphasia, or loss of language, Brijnath says. "The general rule of thumb is 'last in, first out' so if English is your second, third or fourth language, you lose English before the language you might have learned as a little child."

"In many languages there is no word for dementia, or words that are used for dementia are taboo and stigmatising," Brijnath says. "This can cause a lot of confusion and make that whole consultation very difficult."

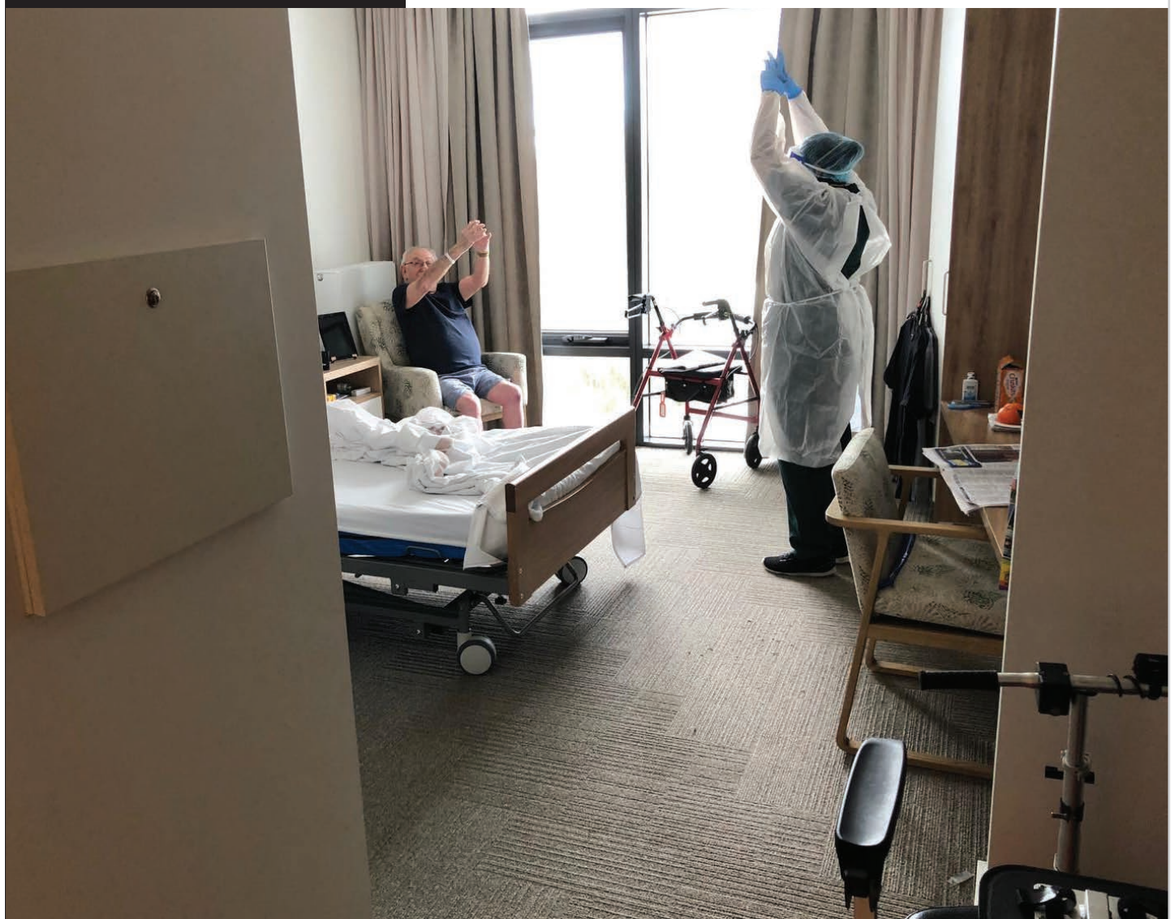
Because dementia often results in difficult "behaviours" such as calling out by residents, aggression or wandering, being able to penetrate the confusion of different cultural backgrounds is critical to good care. As it stands, people from all backgrounds with dementia are often "managed" with drugs or physical restraints by overworked care staff or those with a poor grasp of the causes of these behaviours.

The historical management of dementia in nursing homes has contributed to a near overwhelming aversion to them among older Australians. These fears are based on concerns about loss of autonomy, quality of life and disconnection.

The National Ageing Research Institute's work reinforces other perspectives voiced in this Narrative — that all Australians, and especially those from diverse cultures, express a preference for family and community care over residential aged care.

If there was any doubt about these preferences, a new pandemic erased them.

How COVID-19 changed the game in aged care



The arrival of the Covid-19 virus in Australia and in nursing homes threw the precarious nature of care for the elderly under current arrangements into sharp relief.

Overwhelmingly, aged care providers, at the local and even regional level, did not have staff with high-grade infection control expertise. In early 2020 Newmarch House in Sydney's western suburbs was one of the first nursing homes to experience a sustained, deadly outbreak of coronavirus, which led to the deaths of 19 people.

The final report of the Newmarch House independent review found that both health and aged care administrators and regulatory authorities "often misunderstand or underestimate the infrastructure and training required to prevent microbial transmission, in environments where vulnerable patients or residents depend on hands-on care from busy, peripatetic workers."

In many cases, aged care facilities were revealed as being especially poorly designed for modern care requirements. Some homes were so good at helping spread the coronavirus that it seemed as if they were designed for that purpose. At the same time, newer facilities with plush carpeting and soft furnishings were especially hard to clean.

The increasingly casualised aged care workforce — through no fault of individual workers — also helped spread the virus, particularly in Melbourne, as nurses and personal care attendants picked up shifts at different sites and across different employers.

In the short term, most facilities sought to control infection through strict lockdowns and a ban on all visitors. Overnight, these measures barred a vital source of physical and emotional care: families and loved ones.

Faduma Jama speaks of a very good friend from a Turkish background whose father is in an aged care facility. "She tried to look after him until she physically was unable to do it anymore," Jama says. "Everyday after work she'd go and feed him, spend time with him, look after him. But when lockdown happened, she couldn't get in. The next time she was able to see him she said to me, 'You should see how much he has deteriorated in just that short period.'"

It wasn't just that friends and family members could provide more physical care for their loved ones, relieving over-burdened and low-paid staff in the residential wings. The even greater, though often hidden, value was the emotional nourishment provided by these visitors, especially for those nursing home residents who did not speak English well or at all.

Translation, connection, language — all improve the wellbeing of the body and mind. When these fundamental benefits were suddenly removed, older people suffered.

Dr Ruth DeSouza, a Vice-Chancellor's Fellow at RMIT who examines questions of race, health, cultural safety, birthing and justice, spent time working with older Australians from diverse backgrounds during the pandemic. She wanted to know how they connected with family, friends and services during lockdowns. Her Alone Together project provided insights that went beyond the study of an epidemic to reveal our common humanity.

DeSouza observes a nearly universal assumption from across communities that people from "collectivist cultures" will look after their elderly at home. "Typically that has been the case," she says. "But if you're talking about diaspora communities that might have to work — a sandwich generation that is trying to manage young people, schooling plus someone older — there is going to be tension."

Connection is so easily shattered. For the Alone Together project, DeSouza spoke with a man who was born in Egypt and came to Australia with his family while he was young. Although he worked in a bank with computers, he had no IT services at home and at age 67 had been "dreadfully depressed" for 15 years, DeSouza says.

"He was lonely. It was just really difficult because his closest confidante was his older sister who lived more than 10 kilometres away. He was talking to her on the phone but there wasn't that hanging out time."

Another woman in the study experienced the unexpected death of her brother in his 70s and found it difficult to cope with the loss. "This is someone she knew for more than 70 years and (during the lockdown) you can't have everyone around to your place to just talk about that and do all the stuff that helps you put healing balm on that wound," DeSouza says.

"She was heartbroken. And the other thing she realised was that she didn't know any of her neighbours and all the people she loved and cared about were 5km or more away from her home."

Undertaking this project, DeSouza realised that while dozens of different services already existed in the community or through the three levels of government, many were hidden away.

DeSouza says that when she talked to various organisations they told her, "Oh, we have this program, we have that program, they could get help from here," she says. It reminded her of helping to run the consumer consultation for a supervised injecting facility in Richmond, in inner Melbourne. In many instances, the services people wanted or asked for already existed. They just didn't know about them. "So there is almost a step before that (undertaking a project) — about how you engage people," she says.

Case study 3: Aged care services for Australia's Indian communities

Jay Raman is Vice President and Executive Director of Sri Om Care, an organization created in 2007 by the Sri Om Foundation to provide aged care services for people of South Asian heritage. The organization bases its model of care around the ethos that God is in every living being. By serving society, people serve God and thus live as one. Or as the organization puts it, *Humanity leads to Divinity, Divinity leads to Unity*[1]

Jay has worked in the aged care sector for many years. While working at Uniting Care, he created manuals to help the organisation understand the needs of culturally diverse communities. Recognizing the need for culturally specific aged care, he went on to establish Sri Om Care.

The organisation began by creating a series of day centres in Western Sydney's culturally diverse suburbs of Auburn, Seven Hills, Glenwood, Pennant Hills and Liverpool. They offered light exercise classes, games, social outings and health lectures during the week, with lunch provided for a small fee ($3 to $5). Yet the early years were very challenging, and the centres struggled to get people to come. It took Sri Om Care almost a year and a half to break down the barriers that prevented families accessing their services, even at this most accessible level of care giving. Jay says:

"It took us a long time to convince people, seniors, to come to the centers. Many times their children never allowed them to come. Because they said, 'We know how to take care of our parents. Who are you to take care of them?"

Over time and with perseverance the day centers gained clientele and popularity, peaking pre-COVID at almost 400 elderly

visitors. Through these interactions the organization came to realise that people were seeking higher levels of care. Sri Om Care decided to expand into home-based services, at first using a brokerage model through major service providers like Uniting Care and Baptist Care, who struggled to meet the needs of their culturally diverse clients.

"Wherever there were ethnic populations, they (these providers) couldn't do the service," Jay says. For a small fee, and using its own care workers from South Asian communities, who spoke the languages and had the cultural knowledge to work in these communities Sri Om Care stepped in to provide services.

But COVID-19 changed things. South Asian international students provided one of the main sources of staff for Sri Om Care. With the borders still closed, it has been harder to find people with cultural and language skills to meet the needs of their programs and services.

For Sri Om Care, providing in-home care led naturally to residential care. The organisation could see the lack of facilities that provided spiritual care, food and culture to South Asian communities. It decided to create a small group facility in which six to eight people could live together, close to the community and to their families. The first facility was due to open in Box Hill, Sydney in December 2021.

In Melbourne, efforts are also underway to create a residential facility for elderly community members from the subcontinent in the outer south-eastern suburb of Noble Park. The facility will be run under the auspices of MiCare (formerly DutchCare), an organization that provides aged care for migrant communities in a way that respects their "culture, their history, their language and tastes, and their stories."[2]

The facility, still being developed, hopes to house around 118 people, living on floors of 12 or 15 residents. Aesthetically, it will be modelled on the "symbolic motifs, symbols and colour palette of India." Each floor will feature a distinct colour theme, including yellow (representing commerce and community); red and orange (positive energy); pink and purple (charm and femininity); blue (bravery) and green (peace and happiness).

Pointed archways will give a sense of grandeur and significance to the facility. It will feature communal places for prayer, which will be blessed by local religious leaders, and culturally appropriate food. As many Hindus and Sikhs are vegetarian, meals will be prepared in a vegetarian kitchen.

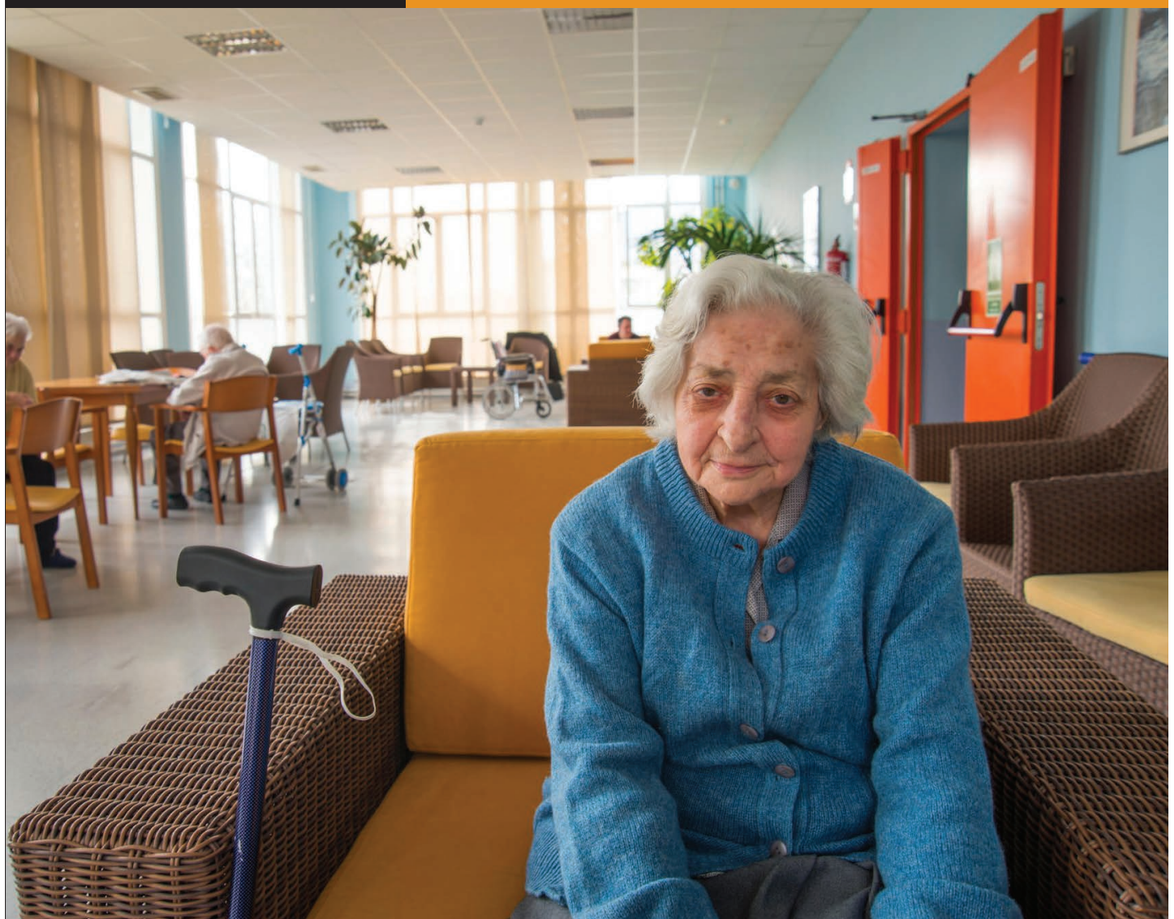
One challenge that MiCare Executive Director Petra Neeleman has found is catering for the burning of offerings and incense—important aspects of Hindu religious practice. Petra says her organisation has worked closely with the Federation of Indian communities in Australia to understand the cultural and religious requirements of different Indian communities. MiCare is considering modern alternatives like 'plug in' incense burners that are able to be used while still meeting health and safety requirements.

While COVID-19 and changes to government funding and regulation have made many aspects of planning difficult, Petra hopes building will begin on the facility soon, and that it will open in 2024.

[1] http://www.sriomcare.org.au/about-us
[2] https://www.micare.com.au/about-us

Conclusion:

Making policy based on love



Time and again, the requirements of culturally diverse people in aged care are sidelined by providers and governments. Agencies and regulators can do this deliberately — it's "too hard" — but more commonly because they lack understanding of minority communities and their needs. The need is to build a better connection between people from diverse backgrounds and the aged care system.

"Everything starts from…when the older person gains an entry point to the aged care system," says Mary Ann Geronimo, health and ageing policy director at the Federation of Ethnic Communities Councils of Australia. "What we have been seeing is that this is a major concern [among consumers]."

A dense and confusing system presents an imposing edifice to the public and people can be at their most vulnerable when they finally need to navigate it. As Geronimo says, it's not enough for the government to point out a few online tools that promise to connect elderly people to aged care services.

Enter the EnCOMPASS multicultural aged care connector, a pilot program run by FECCA.

The concept is simple: find people where they are. The pilot seeks to enlist local religious groups and community organisations to play a role in finding proper care for elderly people. The pilot's work extends into hyper local areas, too. For example, Asian grocers and specialty food stores are included in an informal network that can refer older people from non-English speaking backgrounds to the care and support they might not even know they are looking for.

Geronimo says EnCOMPASS has two vital features that mark it out from other programs: the key role of bilingual, bi-cultural aged care workers and a more community-based approach. In short, the answers to aged care questions under EnCOMPASS are coming from other community members who have been through the system with friends or family. This way, the information provided is more useful and delivered in the terms familiar to a particular community. Top-down government programs tend to use confusing language and can inadvertently act to push people away.

A key recommendation of the 2017 legislative review of the aged care system, conducted by retired senior public servant David Tune, was the introduction of a Level 5 home care package. The additional support would have provided funding equal to the "average cost of residential care" to allow people to receive more complex services, and perhaps even die, at home.

More than four years since Tune completed his review, the problems in the home care system are still being slowly addressed. To date, the Commonwealth has not sought to introduce a Level 5 package.

Although most Australians want the right to remain in their own homes, especially as they near the end of life, even a death at home is a melancholy notion for many older people from diverse cultures, who may wish to return to their homeland to die. Unfortunately, very few people achieve this dream.

"No one is going anywhere," says Faduma Jama. "It's just not feasible. But they all talk about it. Because you have to understand — it is about identity. You won't find somebody my age, who has been raised in Australia, with that nostalgia because they don't know that life."

Jama thinks this generational difference is common across all ethnic backgrounds.

"A lot of research shows that early arrivals — for example, the Greeks and Italians — for so long were like, 'We are going back to the Motherland.' The Lebanese also had that for a really long time."

When people confront death under unfamiliar conditions, far from their birthplace, loneliness can grow. "It even reduces your life expectancy," Jama says. "People become so depressed because they're not really interacting with people who meet them at their level."

One set of powerful responses to the many difficult problems of caring for elderly people from diverse backgrounds might be found at ECH, a South Australian aged care and retirement living provider. ECH is focussed on extending its care to elderly people from diverse backgrounds, including members of the queer community, people with Aboriginal and Torres Strait Islander backgrounds, and people with a disability.

The organisation's CEO, David Panter, is a gay man who witnessed the worst of the AIDS epidemic when it swept through his home country, the United Kingdom, in the 1980s. After training as a psychologist, Panter was planning to move into academia when two events altered the course of his life. Prime Minister Margaret Thatcher abolished the Social Science Research Council — "because community didn't exist" — and then HIV arrived.

Panter became the first person employed by Britain's National Health Service (NHS) to work on the streets as a community development officer whose clients were gay men and injecting drug users.

From there he moved into NHS management and creating Britain's first AIDS services.

Part of Panter's work in London was to set up a buddy system for those caught in the teeth of the epidemic. "We had so many essentially young gay men, completely separated from their families, who had nobody to call on in times of crisis and emergency," he says.

Panter's work history explains why, as he and his colleagues undertook a consultation to reimagine their company for the next five years, the CEO proposed creating a 'lived experience reference group' of about 30 people.

The group was a glorious mix. It included people receiving aged care services from ECH in their homes, those living in retirement housing provided by ECH, and members of their support networks. All that diversity produced one united, simple message: "We want love."

"It's not rocket science," Panter says. For some ECH clients, "our home care staff member who goes and sees them regularly might be the only person they see regularly in their life. So, then, remembering that it's their birthday and taking them a bunch of flowers or a cupcake is love. They want love. They want to be visible."

Panter says that he and his colleagues were keen to renew the organisation's values in more accessible language, avoiding worthy but overused, bland words such as 'integrity'. As they recognised even before they consulted residents and home care clients, providing support might be the policy intent but it is love that ought to be the goal. Not romantic or even familial love, but the kind of love that arises from a shared understanding that all people deserve to be embraced for their human dignity.

Panter believes that such frequent consultations of clients and staff lie behind ECH's success. It enables the organisation to quickly pinpoint needs and to respond.

ECH also has a relationship with a string of community cafes. It works with café owners to identify quiet periods during which residents and other ECH clients can run activities or create networks and friendships. One of the most successful programs in that chain of cafes is the "resident baker" program.

Panter says the program is designed for "people who have had a whole life of cooking for others and now have nobody to cook for. They can go into their local cafe, cook their favourite cake and then it gets sold. It brings such joy to people."

This simple program taps into a profound truth. "It doesn't matter who you are, whatever your circumstances, you always have something to give," Panter says. Being able to give "is part of how you feel good about yourself and is part of having a reason still to live."

The goal for aged care should be is to create a system that can respond to Australia's great and growing diversity. People from migrant backgrounds, and of course even those from the same birth countries, have a constellation of interests and differences.

Across all groups, some people will feel that their culture is the touchstone in their life. Others may see it as a backdrop against which their life has been staged but not the set piece.

This is the central story of diversity. It is the central policy challenge.

Recommendations

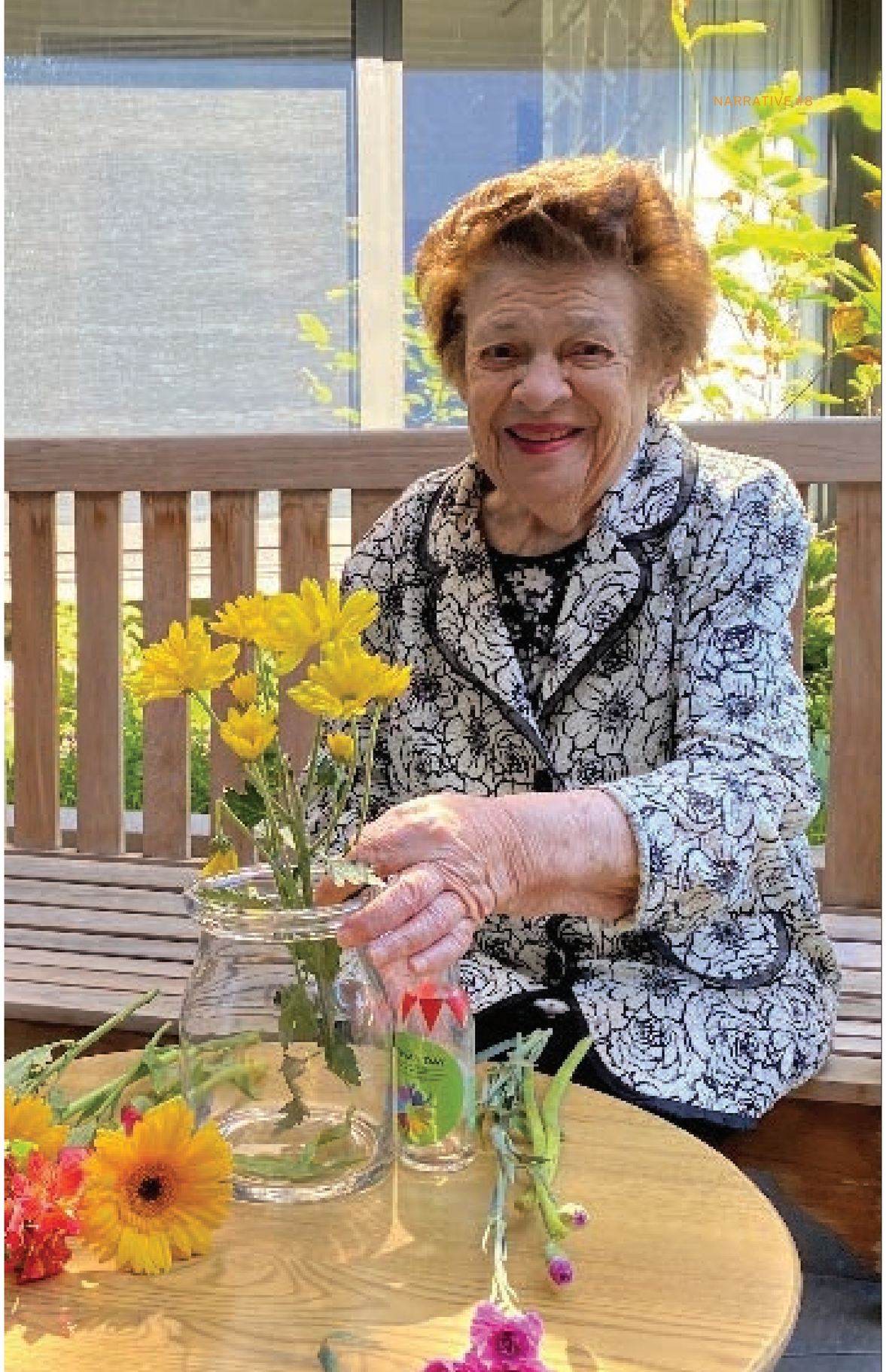
1. Any revision, amendment or replacement of the Aged Care Act should enshrine a rights-based approach for all consumers of aged care services and especially those from diverse backgrounds. This should include the right to timely, well-resourced interpreting services pre-access and throughout a person's time in care.

2. The Commonwealth should introduce a Level 5 home care package funded on par with the average annual cost of a nursing home resident in recognition of the Tune recommendation and the overwhelming preference of Australians to receive care in their own home, closer to their community.

3. The Australian Government should unlock a supply of skilled migrants for the booming care sectors (aged and disability) from a range of different countries and backgrounds, but this should only be done where visas or labour agreements have a strong, legislated minimum wage and tough penalties for employers that do not comply. Such a setting would help prevent exploitation of workers and raise the quality of care in the industry.

4. As per the findings in the Aged Care Royal Commission, direct care hours should be boosted across all levels of aged care staff. We recommend going further than the Commission, however, and introducing minimum staff to resident ratios with taxpayer funding tied explicitly to this provision.

5. The Health Minister and federal Department ought to make entry into the home care sector for community-based organisations simpler and fairer. Such a framework should recognise that home support has benefits beyond the physical care itself, such as access to social connection, language and economic dividends for workers from diverse communities.



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About the Scanlon Foundation Research Institute

The Scanlon Foundation Research Institute exists as a bridge between academic insight and public thought, undertaking research to help Australia advance as a welcoming, prosperous and cohesive nation, particularly where this relates to the transition of migrants into Australian society.

In doing so, the Institute links thought to action to ensure informed debate drives the agenda, and empowers the critical thinking that will help drive Australia's social cohesion forward.

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