Australian Mosaic

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Contents

A Message from the FECCA Chair 1
Mr Pino Migliorino

From the CEO’s Desk 3
Dr Loucas Nicolaou

Editorial: Views on the News 5
Dr James Jupp AM

multiculturalism in practice
Dr Christina Ho

Stories Behind the Policy: Personal stories from
five CALD seniors and carers 9

Meeting the Needs of an Ageing Population 19
Senator Concetta Fierravanti-Wells

COTA’s Involvement in Advocating for the
National Aged Care Reforms 21
Mr Ian Yates AM

Accessing the Aged Care System: the Aged Care Gateway 24
Mr Bruce Shaw

Healthy, Active Older Australians: A social and
economic imperative 28
Ms Mary Patetsos

Delivering Culturally Appropriate Aged Care to
All Australians 31
Ms Elaine Goddard

I’ll Have CALD With That... 34
Ms Rosa Colanero

Dementia Friendly Communities and Organisations 36
Mr Glenn Rees AM

Friend and Family Carers of Culturally and Linguistically
Diverse Australians – Access to Carer Supports
Ms Ara Cresswell

What CALD Carers Really Need 38
Ms Anndey Ho

How Bhutanese Elderly Live in Australia 41
Mr Parsuram Sharma-Luital JP

Sexuality, Diversity and Ageing 44
Dr Catherine Barrett

Supporting Palliative Care for People from Culturally
and Linguistically Diverse Backgrounds 47
Ms Fiona Brooke

What Do We Know and What Do We Need to Know? 50
Compiling the evidence, identifying the gaps and
making research accessible to providers of services
for CALD older people
Professor Graeme Hugo

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A Message from the FECCA Chair
Mr Pino Migliorino

Welcome to the Spring 2013 edition of Australian Mosaic magazine – Healthy Ageing in Diverse Australia. The 16 articles in this edition offer a variety of perspectives on the key priorities for ageing and aged care, and showcase some excellent work being done to provide culturally appropriate care for culturally and linguistically diverse (CALD) seniors, as well as support for their carers and families.

This edition opens with a review of the recently published book, ‘For those who’ve come across the seas...’: Australian Multicultural Theory Policy and Practice edited by Dr Christina Ho and Professor Andrew Jakubowicz, who remind readers of the need for continued discourse on what multiculturalism means in 21st century Australia.

Five personal stories shared by CALD seniors, as well as carers and family members of CALD seniors, powerfully illustrate many of the issues that underpin the articles in this edition: the importance of a care framework that enables seniors to maintain their independence, community involvement and cultural identity as they grow older; as well as the pain of watching a parent develop dementia, and the difficulty of finding care in the local area that is appropriate to both the recipient’s health needs and cultural background. I express my heartfelt thanks to these five contributors for sharing their stories and look forward to FECCA sharing more such stories throughout our various publications over the coming months.

Following the recent Federal Election, newly-appointed Parliamentary Secretary to the Minister for Social Services, Senator Concetta Fierravanti-Wells, affirms her commitment to the reform process and outlines some of the key issues for CALD ageing and aged care from the Australian government’s perspective. Mr Ian Yates outlines Council of the Ageing (COTA) Australia’s significant involvement in the reform process thus far. Mr Bruce Shaw discusses FECCA’s involvement in the development of the Aged Care Gateway, and some of the further steps needed to ensure that the new My Aged Care website is fully inclusive of people from CALD backgrounds.

Ms Mary Patetsos reminds us of the importance of holistic policy that supports the continued social and economic contribution of older Australians. Ms Elaine Goddard continues this focus on healthy ageing, outlining some of the work that UnitingCare does to support healthy living and community involvement for CALD seniors. Ms Rosa Colanero discusses the work of the State and Territory-based Partners in Culturally Appropriate Care (PICACs), the leading authorities on culturally appropriate care, including the Cultural Intelligence framework that underpins their work.

Unpaid carers are the bedrock of community support for older Australians, particularly in CALD communities. Ms Ara Cresswell (Carers Australia) outlines some of the ongoing challenges to ensuring that CALD carers receive the support they need, while Ms Anndey Ho from Carers ACT provides a grassroots

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perspective on issues facing CALD carers and some of the community initiatives that are supporting them.

In advocating for the needs of particular groups we sometimes risk pigeon-holing people under a particular minority banner, such as ‘CALD’, ‘LGBTI’ or ‘refugee’. The danger in doing this is that more complex intersectional identities are not recognised, and groups with multiple diversities become even further marginalised. Mr Parsuram Sharma-Luital JP provides a perspective on the experiences and challenges faced by former refugees from Bhutan as they grow older. Dr Catherine Barrett reminds us of the importance of considering the intersection between ageing, sexuality and cultural diversity, and of changing the way we as a society view older people’s sexuality.

Ms Fiona Brooke outlines Palliative Care Australia’s work with CALD communities to promote culturally appropriate end-of-life care, and Professor Graeme Hugo, Dr Helen Feist and Dr Kelly McDougall discuss a new joint project between FECCA and the Australian Population and Migration Research Centre that will review national research on ageing and diversity.

All of the contributors to this edition share a common goal of ensuring that all Australians understand and have equitable access to aged care services that are appropriate to their needs. All of the contributors to this edition share a common goal of ensuring that all Australians understand and have equitable access to aged care services that are appropriate to their needs. In reading this edition of Australian Mosaic, I am humbled by the enormous expertise that exists on ageing and aged care in CALD communities, and excited by the potential for change and innovation that can be achieved by the increasing partnership by key advocates in this sector.
From the CEO’s Desk
Dr Loucas Nicolaou

Welcome to the Spring 2013 edition of Australian Mosaic, entitled Healthy Ageing in Diverse Australia.

The current aged care system can be very difficult for older people, their families and carers to understand. The sources of information available are wide and varied, often difficult to access and understand and do not necessarily support informed decision-making. People from culturally and linguistically diverse (CALD) backgrounds face particular barriers.

The 2011 Productivity Commission (PC) report Caring for Older Australians recommended comprehensive reform of the aged care sector. The Living Longer Living Better reform program was the former Government’s response, addressing most of the PC’s recommendations.

In order for CALD elders to benefit from the aged care reform process they need to be included in the policies, programs and services that will meet their preferred care needs.

Since commencing FECCA’s formal engagement in the aged care sector in June 2012 with an initial funding grant from the former Department of Health and Ageing (DoHA), FECCA has quickly established its credentials as a leading stakeholder in aged care. From August to December 2012 FECCA worked closely with DoHA to contribute to the development of the former Government’s National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse Backgrounds (the CALD Aged Care Strategy).

The CALD Aged Care Strategy is a useful framework which sets out six strategic goals and 35 actions which the former Government committed to achieving between 2012 and 2017. We are pleased that indications from the new Government suggest it is equally committed to the reform process. It is hoped that the Strategy will be an important enabler of endeavours to support the aged care sector to deliver high quality care that is appropriate and sensitive to the needs of CALD elders. The Strategy will greatly assist inclusion, empowerment, access and equity, quality, and capacity building among CALD people and community organisations by ensuring that all future aged care policy is culturally, linguistically and spiritually inclusive.

FECCA’s role on, and positive contributions to, the various advisory groups to the Government on the aged care reform process have been instrumental in ensuring that Australia’s aged care system moves toward our goals of enhanced CALD inclusion and empowerment. I thank the FECCA representatives on the aged care reform committees, and FECCA’s dedicated aged care staff, for their contributions to FECCA’s positive engagement in the reform process to date.

FECCA has established a Healthy Ageing Reference Committee with wide demographic and regional representation. This committee is developing effective mechanisms for consultation and engagement at State/Territory and local levels.

FECCA will bring together all the FECCA representatives on the aged care reform implementation advisory groups, working groups, and sub-groups by establishing a FECCA Aged Care Reform Representatives’ Working Group as a subcommittee of
the FECCA Healthy Ageing Reference Committee.

FECCA has established the National CALD Ageing Network (NCAN) as a key consultation tool and voice representing the needs and experiences of the older CALD community. NCAN is a web-based communication network for people and organisations involved in the CALD ageing sector to feel empowered and be heard, and is accessible through the FECCA website. The NCAN website can be accessed via the icon on the FECCA homepage (www.fecca.org.au) or directly at http://www.fecca.org.au/about-ncan. We are encouraging anyone and everyone, and all organisations, with an interest in CALD ageing and aged care, to join NCAN online.

I would like to take this opportunity to thank those who contributed personal stories to this issue of Australian Mosaic. If you or someone you know is a CALD person who is ageing, and would like to contribute such an account, FECCA would be grateful for your contribution to a future publication. FECCA is seeking CALD elders, family members, carers and aged care workers who have experiences and views on ageing and accessing the aged care system to profile through various means. We are also seeking opinion pieces on policy issues which we can publish in NCAN News, as well as in Australian Mosaic from time to time, and with which we can illustrate both positive and negative experiences around CALD ageing.

FECCA is delighted to have received additional support from the DoHA Aged Care Service Improvement and Healthy Ageing Grants (ACSIHAG) Fund to assist us to build our capacity, expertise and contribution to the reform processes in the coming period. One grant is specifically for a short-term Systematic Review of available evidence on CALD ageing and aged care. Professor Graeme Hugo and his colleagues’ article in this edition provides further information on the project.

The outcomes of the Review will be a first step to identifying research needs and priorities in CALD ageing and aged care and for pursuing a CALD ageing and aged care research agenda. FECCA is seeking community input in identifying any research, reports and/or references that may be relevant to this review and would appreciate any assistance you may be able to provide.

A second grant to FECCA will be vital to enhancing CALD inclusion by building on and expanding CALD engagement with aged care policy development, strengthening our consultation mechanisms, and promoting CALD capacity building in aged care.

FECCA welcomes the Hon. Kevin Andrews, Minister for Social Services, the Assistant Minister for Social Services, Senator Mitch Fifield, who is responsible for aged care, and the new Australian Government Department of Social Services. FECCA looks forward to working with these and other ministers to further our relationship with the new Government to ensure that the recent moves towards better access to and engagement in quality aged care by CALD Australians will continue and progress effectively.
Modern Australia was founded in 1788 as a prison in the Pacific, far enough away from Britain for its inmates to be unlikely to escape (although some did). The first generation of prisoners were not normally locked away, as there were no custom built prisons for them. Most were on a seven year term which could be reduced for good behaviour. Others were forbidden to return to Britain, but could build a new life in the colonies of New South Wales and Van Diemen’s Land.

Misbehaving convicts could be locked into a chain gang, which mainly worked on roads and public works. Others were sent to isolated prisons on Norfolk Island and at Port Arthur. Escape from these was almost impossible. In very serious cases they were hanged. Although transportation ended in 1840 in New South Wales and Tasmania (Van Diemen’s Land) in 1853, it was continued in Western Australia until 1868. There were still some life-sentenced convicts living in Port Arthur until the 1870s. Prisons in the Pacific were central to the first century of British settlement, until the discovery of gold in the 1850s created several decades of free and uncontrolled immigration. This came to an end with the Immigration Restriction Act, the first major law of the Commonwealth.

Ever since then, immigration to Australia has been bound by increasingly complex laws and restrictions. From 1901 to 1972 immigration was not available to non-Europeans under the White Australia policy. It was free to law abiding white British subjects, mainly from Britain, Ireland and New Zealand. Many of these were subsidised to come to Australia and this was extended to other Europeans after the Second World War.

However, small groups of individuals continued to be locked away from time to time. These included ‘enemy aliens’ during both World Wars, including many of German or Italian descent who had been born or naturalised in Australia. Some were sent from Britain, where they had already been interned on the Isle of Man. All resident Japanese were deported back to Japan in 1945. Another major group were Aboriginal people, who were organised to live in special

From 1901 to 1972 immigration was not available to non-Europeans under the White Australia policy. It was free to law abiding white British subjects, mainly from Britain, Ireland and New Zealand. Many of these were subsidised to come to Australia and this was extended to other Europeans after the Second World War.
reservations, where they were under strict control. These were managed by religious bodies or State Governments. Large numbers of European displaced persons were placed in rural camps like Bonegilla and Bathurst, while many British immigrants were housed in Nissen huts in the industrial areas of major cities. The Europeans were obliged to work under Commonwealth instructions for two years, but this was not applied to the British. Residence in these camps was normally limited to two years and the obligation to remain in them was gradually withdrawn.

Which brings us to 1991 and mandatory detention for those arriving by boat without a valid visa and claiming asylum under the UN Convention of 1951. Detention was originally designed to discourage a mass intake from Cambodia, where about one million people were massacred by the Khmer Rouge government. A larger number of Vietnamese had been settled without this coercion after the fall of Saigon to the Communists in 1975 and the development of a co-operative orderly departure system. Whether mandatory and irrevocable detention was intended to be permanent is not clear. But it became so and remains a major feature of refugee settlement. It led to the creation of many locked centres in remote areas such as Woomera and Baxter, some of which have now been closed. These were managed by private prison companies. To avoid charges that ‘prisons’ breached UN Convention rules, they were always officially called detention centres. Many thousands passed through them, though almost none of ‘European’ origin.

Which brings us to the present policy, which sends unvisaed arrivals by sea away to Manus Island and Nauru. Both of these are much more isolated than Norfolk Island ever was. Nauru is one of the smallest and most remote states in the world. Manus Island lies two hundred miles off the northern coast of Papua New Guinea. Management rests with Australia, the two Pacific states and private prison companies. The enormous cost rests with Australia. Whether it will become a permanent system or simply fade away as others have done will be an interesting study in human management.

Meanwhile, we recently saw an election with the “boat people” issue at its centre. How this ‘issue’ assumed such magnitude is one of many odd features of current Australian politics. I look forward to commenting as it further unfolds.
Book Review:
New book documents Australian multiculturalism in practice

Dr Christina Ho

Dr Christina Ho is a Senior Lecturer, Social and Political Change Group at the University of Technology, Sydney. She researches immigration, cultural diversity, citizenship and identity, and has focused particularly on Chinese migration, Muslim diasporas and immigrant youth and belonging. Christina is currently working on projects investigating cultural citizenship and community arts in Western Sydney (in partnership with Information and Cultural Exchange); the politics of recognition and intercultural relations; and political expression, mobility and citizenship among Chinese and Indian international students in Australia.

How has multiculturalism changed the daily operation of the Australian media, community services, local councils, workplaces, schools, and the arts? How has it transformed community relations, advocacy and national identity? A new book published this month takes the pulse of Australian multiculturalism, providing an invaluable assessment of how multiculturalism works in practice in Australian society.

‘For those who’ve come across the seas...’: Australian Multicultural Theory Policy and Practice, published by Australian Scholarly Press, is a collection of more than 20 essays on the experiences and insights of prominent cultural diversity researchers, policy advocates and practitioners.

Editors Professor Andrew Jakubowicz and Dr Christina Ho, from the University of Technology, Sydney, wanted to explore how Australia’s multicultural reality works in practice.

‘Australia has long labelled itself a ‘multicultural’ society, but the often contradictory rhetoric of politicians differs quite markedly to how it actually works in reality,’ said Professor Jakubowicz.

‘Australians live multiculturalism every day. Whether they’re artists, police, First Australians or community workers, when the policy statements are released the hard work is just beginning.’

Numerous surveys show that Australians in general welcome the transformation of Australia under the impact of immigration, explains Professor Jakubowicz.

‘However, public debate around issues like last year’s Islamist demonstrations in Sydney and contradictory public policies have resulted in an obscure and messy reality of multiculturalism,’ he said.

‘Australia has long labelled itself a ‘multicultural’ society, but the often contradictory rhetoric of politicians differs quite markedly to how it actually works in reality,’ said Professor Jakubowicz. ‘Australians live multiculturalism every day. Whether they’re artists, police, First Australians or community workers, when the policy statements are released the hard work is just beginning.’
Dr Ho said the book was less of a discussion on multicultural theory or philosophy as it is about ‘everyday’ multiculturalism.

‘The book examines how multiculturalism plays out in the various arenas of our social lives, from the media and the arts, local and State Governments, to workplaces, schools and beyond,’ Dr Ho said.

‘It provides an overview of what multiculturalism looks like in practice in contemporary Australia, and offers some suggestions for addressing the most urgent problems confronting our diverse society.’

The volume also includes chapters on:

- a history of Australian multiculturalism;
- comparisons of Australian multiculturalism with overseas models;
- settlement and community development;
- disability services and multiculturalism;
- State and local Government multicultural policies;
- temporary immigrant workers;
- security and multiculturalism;
- language policy;
- Indigenous Australia and multiculturalism;
- religion and inter-faith relations;
- racism and anti-racism; and
- case studies of the Australian Multicultural Foundation, the Federation of Ethnic Communities’ Councils of Australia (FECCA), Migrant Resource Centres, and the Special Broadcasting Service (SBS).

The book is an important resource for community and policy workers, researchers, students, and anyone interested in understanding the current realities of Australian multiculturalism.

‘For those who’ve come across the seas...’

_Australian Multicultural Theory, Policy and Practice_ is available in selected bookstores and online at www.scholarly.info/book/351.
Stories Behind the Policy:
Personal stories from five CALD seniors and carers

FECCA believes that telling people’s stories is one of the most powerful forms of advocacy. A person’s story can cut to the heart of the issue and promote understanding in a way that statistics and policy analysis can hardly do.

The following five stories offer a variety of perspectives on ageing: Sonia Di Mezza speaks about the rich and varied life of her much-loved mother, who recently passed away in the Italian village she was born in. Marianne Pieterson emigrated from The Netherlands, first to the US and then to Australia to look after her ageing mother; she is now growing older herself and speaks about the importance of staying busy and involved in community life. Tamara Makeev tells her story of fleeing war-torn Poland before her and her husband immigrated to Australia and became pioneers of the Snowy Hydro Scheme in the 1950s. Their stories illustrate the hybrid identity that many immigrants develop throughout their lives, and the great importance of maintaining their cultural identity, and independence, as they grow older.

Nicole Zabbal tells her story as a carer for her ageing mother, who suffers from dementia, and her ongoing battle to find her culturally appropriate care that allows her to stay connected to her family and community. Danijela Hlis sums up many of the issues that affect older people from CALD backgrounds, as well as their families and carers, from her perspective as a bi-cultural social support worker, Diversional Therapist and carer to her parents.

FECCA thanks all five contributors for sharing their stories and hopes you enjoy reading them. We look forward to sharing more stories from older people from CALD backgrounds, their families and carers over the coming months.

Ms Sonia Di Mezza – Coming Full Circle

Mum was born in 1934 in Formicola, a tiny ancient town, nestled in the valley of a fertile green mountainous region in the countryside of Naples, Italy. Growing up, she and her family experienced the horrors and deprivations that poverty and war often bring. There was never enough to eat and not enough money to support her and her three siblings. Mum had to cut short her schooling because her parents could not afford to send her. However, when I was small Mum told me that those years growing up in Italy were very happy ones. She would often say to me, my brother and sister, ‘you kids have everything here in Australia. Lots to eat and lots of toys. But I tell you, when we were younger, even though we were poor we were a lot happier than you are.’ I came to learn from that comment that what makes you happy is not based on how much money you have but rather how much love you have in your life.

In the fifties southern Italy suffered greatly as a result of the war while Australia was prospering in all areas. When my mother’s relatives in America offered to pay for the family to travel to Australia to live they jumped at the chance. Mum and her siblings couldn’t believe their eyes on the cruise liner that transported them to Sydney when they saw the buffet tables were overflowing with delicious dishes. After dinner they would sneak little titbits from the table and stuff them into their pockets, afraid that they wouldn’t have the chance to eat so abundantly again, only to be surprised by even more overflowing buffet tables at the next meal. The family soon
understood that the days of never having enough to eat were a thing of the past. This new sunny country beckoned them. The cruise liner carried not only Mum and her family but all their hopes and dreams for a bright and prosperous future.

Mum met my Dad in Sydney. His country town was located less than an hour away from Formicola. It was great to find a life partner who came from near to where Mum was born, who could speak her Neapolitan dialect with her, and who could understand her well. Last year my parents celebrated their fiftieth wedding anniversary. Theirs was a marriage based on mutual respect, love and understanding. Although it was a very traditional marriage, with Mum doing all the housework while it was Dad’s role to earn the money to support the family, it was a union that worked well.

Over the years my parents welcomed my brother Joe, my sister Anna and lastly myself into their lives. They worked hard to ensure that we lived in a nice house, ate well, had nice clothes and went to the best private schools in Sydney. Mum would work at home, sewing cushion pieces for a factory. Dad worked as a plasterer, sometimes seven days a week. My siblings and I shared a happy and loving childhood and upbringing.

Life was filled with those little nuances that characterise the lives of many Italians living in Australia. The huge Italian weddings of our relatives that we attended as children until the early hours of the morning; ‘tomato days’ when the whole family would get together to boil, puree and bottle ripe tomatoes for our pasta sauce; the huge family tray of delicious polenta my Mum would prepare, which we would gather around to share for our dinner. So many memories that made us the Italo-Australians that we are today. Not like our cousins back in Italy and not even like our neighbours’ kids; but a different type of Australian, where we would weave the influence of our parents into the very fabric of our lives.

As my parents got older they bought a terraced house in Formicola. After retiring they would go back to Mum’s town in Italy every two years where they would enjoy relaxing in the countryside, surrounded by their relatives and friends.

In April this year Mum and Dad went back to Formicola for one of their visits. One of the first things Mum said to her relatives upon seeing them again was that ‘I want to die here in Formicola’, a comment which they laughingly brushed off, telling Mum that she had many years left to live. Soon after their return to Formicola Mum suddenly became very sick and two months later she died in her village. Her death was unexpected and shocking for all of her family.

But standing on the altar, delivering the eulogy at her funeral and looking out at the pews of people who had come to pay their last respects, it struck me how much my Mum was loved by those who knew her. The church was packed with people from the town who had grown up with Mum and who knew her well. She had her children and grandchildren in Australia who loved and adored her. She had begun her journey in life in Formicola and this was the place where she would end that journey. Her life had been one long adventure, enriched by the opportunities and the realisation of her dreams in Australia. For this I can only be grateful.

So much bad press is given to the plight of refugees and immigrants, to the fear of the threat of multiculturalism, that sometimes the positives that are brought to our country from those born overseas are forgotten. I think back to those days growing up in Australia to an Italian family and wouldn’t wish to change them for the world.

So for now I wish a loving farewell to the gentle, small but big in character person that was my Mum. And I give thanks that she had the opportunity to immigrate to Australia and make her contribution to this wonderful country all those years ago.

Teresa Di Mezza
Ms Marianne Pietersen  
– An Aging Immigrant in Australia

I was not your typical immigrant when I moved to Australia. I was 45, divorced, held two academic degrees and had 27 years of work experience. I had lived for more than 20 years in The Netherlands, one year in Italy and 20 years in the USA. So why did I come to Australia?

The visa I arrived on said it all: ‘Family reunification’. Not that there was a lot of family here, just my brother and his new Australian wife (his third), and my 80-year-old mother. And she was the reason I came. My mother had retired as a teacher in The Netherlands, and after travelling for some years, she had accepted my brother’s invitation to move to his home in WA. She was 76 at the time. She was aware of the risks, but went anyway.

After Mum’s arrival she found that the new home where my brother and his wife lived was in the country, one hour outside Perth, on a dead-end road. No neighbours, only sheep and birds. My brother and wife both worked so Mum got lonely. She bought a small car and visited the nearest village and towns. There she met some Dutch people, played bridge, found a doctor and the shops she needed.

After a few years Mum decided to make a trip around the world. She came to visit me in Florida and while there she was diagnosed with congestive heart failure. The doctors advised that she shouldn’t travel alone anymore, and no long trips. We decided I would move to Australia to go live with Mum in Perth.

So when Mum was 80 I went to live with her, to help look after her. After two months I found a job at Curtin University and we bought a small house nearby. By bus, Mum made weekly visits to the WA Dutch Club, a one-hour trip. There were two medical centres in the suburb, local shops about two blocks away, and across the street was a school, sports fields and tennis courts. Mum was pretty happy watching the kids play sports.

Then she got sick, an ulcer in the oesophagus. After one week in hospital and some blood transfusions she came home, very weak. Her heart condition didn’t help. As I had to work, we arranged for the Silver Chain to visit her. There was also a Dutch Care organisation that sent a social worker and retired Dutch immigrants to visit homebound Dutchies.

Mum’s spirits improved again, but she never got strong enough to go back to the card games at the Dutch Club. When I was two years in Perth, my job at the university finished. I was offered a job with the Commonwealth Government in Canberra, and started planning a move. Then Mum died. She had been looking forward to living in Canberra, but her heart gave out.

Thus I moved to Canberra by myself in 1992. At first I lived in Kingston and worked in Civic. Then I moved departments and worked in Tuggeranong. I bought a house in Kambah. The bank gave me a 25-year mortgage, but at 50 I didn’t think I’d work until 75. So I concentrated on paying off the house as quickly as I could.

I worked long hours, and joined a variety of social and cultural organisations. I became secretary of the local Dutch Club, a position I held for 10 years. I represented them at Ethnic Communities’ Council meetings. During vacations I went to conferences in other capital cities, driving and visiting friends along the way.

Many years of long hours sitting in an office and a fall at work aggravated an old back condition. This gradually became worse, till in 2000 I suddenly couldn’t move at all and had to have back surgery. Fortunately I had enough leave to cover the subsequent absence from work. After four months I was back at work full time, but continued to visit a physio on a somewhat regular basis.
Four years later I aggravated the back again and began working part-time. After two years of this I was offered a redundancy and retired. I was able to pay off my house and live on a combination of super, overseas and age pensions. Around this time I had started Pilates classes that helped with my back condition as well as keep the rest of my body in working condition, as arthritis too had come calling.

I didn’t want to sit home too much, so I volunteered to do a Dutch community radio program, joined the committees of a number of cultural and science organisations and generally got busy. I’m still doing a lot of these, as well as attending theatre, taking a friend to concerts and activities at our national institutions.

One thing that was suffering was my house. After the back surgery I wasn’t supposed to do things such as vacuuming and standing on ladders. While working, I had a private cleaning lady, but after retiring this became too expensive. It was suggested I approach Communities at Work, and through them I now have subsidised Home Help cleaning and gardening assistance. I’m very pleased with these services as they help keep my house in reasonable shape. As I’m developing more age associated problems, I’m planning to move into a retirement village. This will allow me to continue my volunteer activities as long as possible.

Ms Tamara Makeev OAM – ‘Friends help each other’

Tamara Makeev was born in 1923 to Russian parents in the Polish city of Poznan. Her parents emigrated to Poland during the Russian revolution, as they risked persecution because of her father’s position as an Officer in the Tsar’s army. However, the family found themselves in danger again in 1945 when the Soviet army was advancing on Poland. All former Tsarist army officers and their children were to be deported to Siberian concentration camps.

Tamara narrowly escaped this fate when she caught the last train out of Poland to Berlin before the Soviet army arrived at the beginning of 1945. Sadly, her brother and father were less fortunate. They remained in Poland and were deported to camps in Siberia, where her brother died aged just 25. Her father spent 13 years in these camps, and was already gravely ill when he finally returned to Poland.

Tamara stayed with friends in Berlin, but soon needed to leave again as the Soviet army approached. She spent the next few months in hiding, sometimes hiding in forests to avoid capture and deportation. She eventually reached a displaced person’s camp (a “DP camp”) in Munich opened by the United Nations, where she stayed for two years before emigrating to Australia.

It was in this camp that Tamara met and married her Russian husband, Kiril, who came from Serbia, in 1947. After years of displacement and uncertainty they had learned to be industrious – their wedding bands were made from melted silver coins. Tamara hand-sewed her wedding dress from pieces of white silk taken from an old Russian military parachute. Her husband’s wedding suit was made from two American officers’ woollen blankets, died black and tailored into a suit. Tamara still has her dress. The stitching and tailoring is impeccable, and more than 60 years later it still looks stylish and timeless. Tamara’s granddaughter has asked her to keep it so she can wear it on her wedding day.

Tamara and Kiril married at a displaced person’s camp in Munich in 1947.
While in the displaced persons camp, opportunities began to arise to emigrate to countries as diverse as Argentina, Iraq, the US and Australia. While Tamara was tempted by the chance to immediately have her own house and domestic help in Iraq, her and Kiril decided to go to Australia, as specialists were needed to work on a new project called the Snowy Mountains Hydroelectric Authority Scheme. Like many other post-war European immigrants, Kiril would be bound by a two-year work contract in exchange for free passage to Australia. After two years in the Munich camp, they boarded a ship bound for Sydney. After a dreadful month-long voyage via the Suez Canal, they arrived in Sydney on 30 September 1949.

What was Tamara’s first impression of Australia? ‘It was hot,’ she says of Sydney in December 1949. They were housed in old army barracks with corrugated iron roofs, and the first food they ate was a thoroughly Australian meal of chops and peas. The new flavours weren’t the only new thing about their first Australian meal – the food was moving. ‘This was our first introduction to Australian blowflies,’ Tamara laughs, recalling that first meal wriggling with maggots. Tamara and Kiril’s youth and sense of adventure – Tamara was 25 – enabled them to embrace the unknown and see these harsh conditions as an adventure during their first few years in Australia.

Kiril was soon contracted to work on the new Snowy Hydro Scheme in Jindabyne, and Tamara had to stay on her own at the barracks. But Tamara and Kiril were luckier than most post-war immigrant couples from continental Europe, who had to live apart for the duration of their two-year working contracts. Their ability to speak English and several other languages enabled them both to work in Bathurst, NSW, as interpreters at the Commonwealth Immigration Centre. Because Kiril had a permanent job on the Snowy Hydro Scheme as a geodetic surveyor he was not considered a ‘burden’ by the Government, and successfully applied for Tamara’s release from her two-year working contract. Tamara was able to join Kiril in Jindabyne after six months. There they lived in an old farm house near the Snowy Hydro Scheme work site. They were true pioneers, living with no electricity, running water or civilised facilities until the Snowy Authority built proper houses for their workers.

Their new home was far from luxurious, but Tamara says that after years living in basic conditions with no certainty of a future in any place, they had developed a healthy sense of adventure and learned to make the most of what they had. ‘We were young, so it was exciting,’ Tamara says of her experience in Jindabyne. ‘I had to chop wood for the fire, I kept chickens and planted a garden. We either used rain water or had to fetch water from the creek half a mile away.’ The workers’ camp was three miles from old Jindabyne (and the nearest shop), so she would regularly walk the distance to town.

‘But life was lonely,’ says Tamara, as her husband had to work in the Kosciuszko mountains and was only able to come home to Jindabyne on weekends. Sometimes he only made it home once a fortnight, because snow often made the roads impassable and transport was not available. When Tamara became pregnant, she gave birth alone in Cooma because Kiril was stuck in the mountains. It was Summer and the air was black with bushfire smoke.

Kiril was eventually transferred to the Snowy Hydro headquarters in Cooma, where they lived for five years before moving to Canberra, which finally became their permanent home. Tamara says that ‘life
began in Canberra’. The couple could finally put down roots after years of constant moving. ‘I became involved in the community; I joined the Russian church and lots of other groups.’ She and Kiril became Australian citizens in 1954, five years after their arrival.

Although Tamara will soon celebrate her 90th birthday, her busy life and community service – recognised with multiple awards, including an Order of Australia medal in 1999 – has barely abated. She is an active and long-standing member of the ACT Multicultural Council, and of the Belconnen Senior Citizens club. Tamara has always been an active member of Canberra’s Russian community. She coordinated a Russian dance group – sewing the group’s costumes herself – and church choir, often singing at nursing homes in languages as diverse as Russian, Polish, German, Italian and Spanish.

In 1988 Tamara’s singing talent saw her selected as one of 125 representatives to sing at the Sydney Opera House. She sang in a combined choir from various Russian churches around Australia to celebrate the ‘Millennium of Russian Christianity’. She is also a keen amateur photographer and has travelled to different parts of Australia to exhibit her work as a member of ‘Multifocus’, a photography group in Canberra. Tamara was one of the first entrants in the Life’s Reflections Photographic Competition. She has one four prizes and is now the oldest entrant for the 10th consecutive year. Tamara values photography not only as an art form but as a way to preserve ‘good, unforgettable memories’, and her house is full of photographs.

Tamara also attends the Canberra Multicultural Senior Citizens Network (SMiLe). She has made friends from many different cultural backgrounds through SMiLe, including Filipino, Polish, Italian, Dutch and others. Tamara loves this cultural diversity – ‘we all live in harmony and we are all friends,’ she says – and knows that she has many different friends to call on should she ever need help.

This community support is part of what has allowed Tamara to maintain her independence and continue living at home on her own, following Kiril’s passing nine years ago. ‘Friends help each other,’ she says. Her help caring for ageing friends has been repaid, and now their children are there to help wherever she needs it. She also has a community care worker help clean her house once a fortnight.

However, Tamara says that she cannot do the things she used to do. ‘It gets harder when you lose your independence,’ she says. In particular, things are more difficult for her now that she cannot drive long distances. ‘But the main thing is that I am still mentally alert. You can always find ways of getting around physically, but there isn’t much you can do once you lose your mental alertness.’ Tamara says keeping busy and remaining on her various committees helps her stay active and well. Most importantly, she says, ‘I always think positively.’

Tamara says that it is much harder for older people who do not speak good English or who don’t have the kind of community support that she does.

Tamara knows that her care needs may increase as she gets older, and she may not always be able to maintain the level of independence that she currently enjoys. ‘But,’ she says, ‘I’m not going to a nursing home. I’ve seen too many things happen there.’ She says she has a friend in a nursing home and is concerned about him. ‘They don’t look after them properly, they don’t feed them properly,’ she says. Tamara says life in a nursing home is simply not an option that she will ever consider, and she is saving money so that she can afford to pay for full-time home help if she ever needs it.

What are her hopes for the future? Tamara says she wants to see her son, who is battling cancer, get better, and to know that her four grandchildren and two great-grandchildren are okay. ‘Then I can go peacefully,’ she says.

As told to Melanie Tulloch, Policy Officer at FECCA.
Ms Nicole Zabbal – Yes, my work is personal

Going through the arduous task of searching for a suitable residential aged care facility for my mother and hearing an abundance of stories I wish I hadn’t, I am struck by an acute realisation that my decided outcome will by default fall terribly short of her needs. Nonetheless, I now find myself with the unenviable task of single-handedly leading a campaign to persuade my family into believing that this facility is the best thing for Mum, who is well into her eighth year with Alzheimer’s.

This comes after finally being successful in organising to have my Mum placed in respite care that was to provide my ailing 82-year-old father with much needed respite. When both of these visits ended in distress for both Mum and the care workers, the staff explained that ‘for perhaps one-fifth of dementia patients, respite care may not be an option’. In other words, they were telling me that my mother is one of those 20 per cent of clients that would not be cared for overnight. This reality and sense of failure not only compounded our difficult situation, but was also a significant setback in our attempts one year later to find Mum a place in residential facility for full-time care. It became clear that my mother had become burdened with a record for being ‘difficult’. She was denied access to our preferred facility, even to a waiting list. Now time is ticking for my campaign to come into effect before the unavoidable crisis point.

Even so, Hammond Care in Greenwich has been there for us in the form of two professional coordinators, Karen Cope-Williams and Janet Flower, who led us through a range of daytime services, activities, opportunities and care workers. Every family faced with dementia needs a constant, professional advisor to support them through their dilemma. We were blessed with two.

Dialogue with such professionals was our strength against the burden of organising care while managing our own work and families. The coordinators listened, reassured, guided, provided support and even shared their own personal stories. What a powerful professional gift to give. They turned the myriad of written plans into opportunities for meaningful conversations about telling moments through anecdotes that allowed for a deepened understanding and acceptance of the incongruous facets of dementia.

The message for family members is to actively seek and
recognise such professionals as the key to surviving your ordeal. It takes drive, perseverance, confidence and strong communication skills to connect and be led through that great labyrinth of aged care services, but I urge others to go ahead and establish a personal connection in whatever language.

Of vital importance for families like ours from culturally and linguistically diverse (CALD) backgrounds faced with Alzheimer’s is also for professionals to ‘share the personal’ through a simple smile that allows for uplifting moments. At Mydental Care in Sydney’s North Strathfield, Dr. Julia Hu (a dentist) and Sherene Iranzadi (a surgical dental nurse) turned what would have been traumatic visits to the dentist into personal joy. I watched with gratitude and relief as they bridged the cultural and linguistic divide through their personal warmth. Such gems of ‘culturally dementia-friendly’ professionals are few and far between. Professional artist and singer song-writer Jeannie Lewis, who shared her compelling voice with Mum by casually engaging her in French song over a coffee, is another heart-warming model for building bridges that break through the trap of dementia.

My elegant, dignified Egyptian-born mother, Josephine Zabbal, was a professional, literary woman eloquent in three languages and open to learning all. My mother was the drive behind the family leaving Egypt for Kuwait after the Egyptian revolution of 1952, and later emigrating to Australia with their three daughters. Josephine arrived just in time for the opening of the Sydney Opera House in October 1973, symbolically marking her determination for us to embrace Australia unconditionally in our yet-to-be-inhabited outer-Western suburb of Sydney. My mother enjoyed a long working career here as an executive secretary, and was instrumental in supporting my father to set up his small business.

Josephine is a self-made historian and collector, with volumes of unpublished materials about life during la belle époque – the pre-WWII era of optimism and progress – in Cairo. With our help, she is now reliving her own past through her fourth and sadly only remaining language – her extensive collection of European and Middle Eastern songs from the 1950s to the 1980s, all neatly catalogued by artist and title. Even at this late stage of her unfortunate disease my mother continues to exude a human elegance and dignity based on a lifetime of giving and worldliness and that is all too rare. Her love of life and people of all cultures continues – and she has ingeniously developed the skill of covering up her dementia by simply calling particularly caring persons ‘habibi’ or ‘my darling’, thus allowing them to continue believing that she recognises them.

The message again is clear: The heart needs to feel. To achieve relevance and effectiveness with dementia patients, aged care representatives need to connect personally and work together to unlock what is at the core of the person trapped by this miserable disease. Professional services must include structured avenues for new and untold histories to emerge.
Ms Danijela Hlis – 
Diversity and ageing: a carer’s perspective

As a carer, I lived with and for my parents for 15 years. It was time well spent; difficult but enriching. When I look back on this time, I remember the all too common feeling of loneliness experienced by many CALD seniors, and the great importance of education and inclusion.

Loneliness

I first became aware of the loneliness of many our seniors when I befriended a lady in a nursing home on the east coast of Tasmania over 20 years ago, through a Red Cross volunteering program. She had stopped eating. I am reminded of a quote by Victor Frankl, who said, ‘The most widespread form of suffering in the western culture is loneliness.’

Residential care facilities are full of people but often full of loneliness. We should encourage better home care packages. To be alone at home is not necessarily lonely; the old house is full of memories, and there is usually the garden, the neighbours. As a bi-cultural social support worker and

Life is a coin, you can spend it in any way you wish, but you can only spend it once.

As a carer, I had clients on Extended Aged Care at Home (EACH) packages, who loved talking about the good old times in their mother tongue. Sure, some are often incontinent, forget to eat regularly, may forget how to change the channels on their TV, but they are content in their homes, surrounded by memories. They refuse categorically to move to a ‘safe’ residential care facility.

Education

I believe that the lack of education about ageing, wellbeing, prevention of illness (including dementia) and the variety of services available, is greatly responsible for the stigma associated with ‘being old’. This is why we all need to share our stories. We need to go into schools, into large companies with middle-aged employees, into universities training future doctors, and spread the message: ageing is a fact, not a choice. Every GP should feel responsible to give out brochures on independent living and other topics relevant to older people.

Inclusion

Being of culturally and linguistically diverse background is sometimes a disadvantage; often our English is far from good. As a volunteer advocate for my local Migrant Resource Centre, I have helped a man get admission to hospital (after he had been waiting for nearly a year in terrible pain), another get an Aged Care Assessment Team (ACAT) assessment, and another to have a new passport issued to be able to go back to his country of birth. I have been asked to visit newly admitted...
clients in facilities to inform the management what language they spoke.

I would like our community to understand that to have two cultures and to speak two languages is more empowering and enriching than having a million dollars in the bank! We have interpreters and we have created so many beautiful bilingual books, posters and talking albums; and yet these tools are often not used by our day care respite facilities or residential care facilities, or offices dealing with the general public. CALD community organisations, clubs and churches need to play a more proactive role to improve this situation.

Aged care is not just about survival, profit and accreditation. It is about love and compassion and quality living. For many cultures, a nursing home is a terrible place where you go when you have no family and friends. You go there to die. Let us not forget the enormous contributions our immigrants have made to Australia. Person-centred care is a mandatory concept in aged care. I wish the Government would spend less money on military intervention overseas and more on our health and ageing needs.

We all know that many social support workers of CALD background, like me, are now in their sixties. We are not giving enough emphasis to the training needs, to the use of bi-cultural tools, to the importance of talking books, talking albums.

Heinemann Publishers brought out an anthology, entitled *Australian Mosaic* (1997), that was used as a textbook in secondary schools. My bilingual poem *I want a job for my Daddy* is included. The book educated and helped our younger society understand the themes of journeys and immigration. I believe it is time for another such anthology to enter our schools – the joys that my nephew and my mother have shared in the past 12 years are incredible, and this would not have been possible if the little boy was not brought up as a bi-cultural child who respects elders.

During the first few years of being carer to my parents I lacked support and became very ill. Our GPs never informed us of the various support services available, my mother was misdiagnosed for four years and it was difficult to find my way around the system. I believe we carers need a Coordinator; someone who is there for us from the beginning to the end, to offer concrete information on where and how to access counselling, training, respite, health services and financial support.

Once I found out about the support services available, I was extremely lucky that we got a bi-cultural support worker to look after my parents for one weekend per month. I also had access to other support workers through my parents’ home care packages; they spoke no languages other than English but had lots of compassion. But when we moved to another town, we were under a different service provider and only received three hours care per week.

I would like to see uniform care packages based on assessment and needs, not on where one lives. I would like the State and Commonwealth Governments to acknowledge the millions of dollars that we, family carers, save this country, and re-invest these in aged care reforms and dementia research.

Danijela’s published works can be viewed at http://www.austlit.edu.au.

If you have a story you would like to share or know someone who does, please visit the National CALD Ageing Network (NCAN) website at http://fecca.org.au/we-want-to-hear-your-stories for more information.
Meeting the Needs of an Ageing Population

Senator Concetta Fierravanti-Wells

Senator Fierravanti-Wells was born in Wollongong NSW. As the daughter of immigrants from Italy, she has a long-standing interest and involvement in the Australia-Italian community. In the early 1980s, she was a founding board director of an aged care facility in the Illawarra, which was a joint venture between the Italian community and a major not-for-profit provider. Concetta has continued her interest in ageing issues over the years, both as a federal politician as well as a person who experiences the day-to-day needs of her parents supporting her mother who cares for father who has dementia. Concetta became a Senator on 5 May 2005 filling a casual vacancy.

This article was authored prior to the Federal Election on 7 September 2013 while Senator Fierravanti-Wells was Shadow Minister for Mental and Ageing.

The ageing of our population is the biggest social issue facing Australia. Australia has a rapidly ageing population. We are living longer. As we are ageing, we have more complex health conditions and changing disease patterns, resulting in changing aged care needs.

Additionally, we are experiencing a shift in the size and composition of households. The implications of an ageing population, including an increasingly larger culturally diverse ageing population and the need to increase care services, are challenging.

It is important that we formulate policies that can actually be delivered on. There is growing and alarming evidence that the aged care sector cannot provide the care that Australians expect. Until there is proper structural reform of the sector, the care and wellbeing of senior Australians is at risk.

We know budgetary pressures cannot sustain Australia’s demographic changes and the declining workforce will generate insufficient tax revenue to meet the health and aged care demands of our ageing population. The dependency ratio in 2007 was 6.0 working people to support every person aged 67 years and over but by 2047, this will be almost halved to 3.2 people of working age.

As indicated, Australians are living longer. With longevity, the complexity and expectations of care needs increase. Over 85-year-olds, which are the main users of aged care services, will increase from 400,000 (1.7 per cent of the total population) in 2007 to 1.6 million (5.6 per cent of the total population) by 2047.

But more startling is the projected increase in dementia from 245,000 people in 2009 to 591,000 in 2030, to a staggering 1,130,000 people by 2050.

The Coalition is committed to ensuring older Australians have the care they need, where and when they need it. To enable this to happen, those providing such care should have all the support, certainty and flexibility they need to remain sustainable and free to do what they do best – delivering high quality, dignified care to those who need it.

Ageing covers the broad spectrum from well-being through to palliative care and much in between. We look forward to working with the ageing sector to achieve reform as part of our first ever five-year provider agreement.

Our agreement will be a partnership with the sector. We will seek to reduce the red-tape and administrative burdens faced in the sector, provide greater investment certainty, allow easier and more direct input into Government decisions and pave the way for
better choice and outcomes for older Australians, their families and carers.

As I have travelled over all parts of Australia as Shadow Minister, I have heard from many people that there are major concerns with many aspects of how services are provided to older Australians and more importantly, where and when they are available.

The Productivity Commission released a report in 2011, *Caring for Older Australians*, which made recommendations for change and reform in many areas of what, how and where services are provided to meet the needs of senior Australians as they grow older and need help in various ways.

This was a report commissioned by the Australian Government. It received close to 500 submissions, and its draft report generated almost as many submissions again. The final report was welcomed with widespread support for the thrust of the recommendations it contained.

One of the specific areas that interests me in particular is that we need to recognise there are increasing “special needs” in all areas of care for older Australians.

This is very much the case in our culturally and linguistically diverse communities. The current system does not cater well to our diversity. As one in four Australians come from other cultural backgrounds, their needs as they age are different and unique. If we are to ensure that the needs are met for people from these differing cultures, then we have to accept that we need to provide facilities and services that meet those special needs.

Increasingly, providers both in the residential and community sector are advocating for greater flexibility so that a language other than English can become the primary way of communicating with older Australians from culturally and linguistically diverse (CALD) backgrounds. There is no avoiding the fact that as people who were born overseas experience dementia and other declining health conditions, they frequently lose their capacity to speak English and revert not only to the language of their youth, but frequently back to local dialects of those languages.

I think we should be striving to provide services and facilities to the growing number of older Australians with those unique backgrounds. Australia continues to mature every day in many ways. Part of that maturity is accepting that we are a country of many different racial backgrounds and that diversity is valued as part of what makes this country what it is today.

A Coalition Government will work towards meeting those different needs right across the ageing sector in both community and residential ageing services.
CoTA’s Involvement in Advocating for the National Aged Care Reforms

Mr Ian Yates AM

Mr Ian Yates is Chief Executive of COTA Australia, a role he has held since June 2009. He has also been Chief Executive of COTA SA since June 1989. Within the COTA network Ian holds a number of other positions including Chair of COTA Member Services, Director of COTA Insurance Services and CEO of the COTA National Programs Unit. He is a Board member on the Aged Rights Advocacy Service which is auspiced by COTA SA. Ian serves as COTA representative on a wide variety of Federal and State Government bodies, as well as aged care sector national bodies. Ian is also Deputy Chancellor of Flinders University, a member of the Australian Institute of Company Directors and was awarded the Order of Australia in 2005.

COTA Australia is the national policy, representation and advocacy organisation of the COTAs (formerly Councils on the Ageing) in every State and Territory. The COTAs have over 1,000 member organisations reaching over 500,000 older Australians, as well as 40,000 individual members.

COTA has a long history of involvement in efforts to achieve a higher quality, consumer-driven aged care system offering real choice and control to people in need of care. COTA supported the 1989 report on Residents’ rights in nursing homes and hostels that gave birth to a Charter of Residents Rights and the National Aged Care Advocacy Program.

Aged Care undertaken in 2004 by Professor Warren Hogan, and I was a member of confidential Commonwealth working groups on the long-term issues identified by Hogan under then Ministers Julie Bishop and Santa Santoro.

COTA was a founding member of the National Aged Care Alliance (NACA) in April 2000, established to bring provider, union, professional and consumer groups together to work on developing a united policy agenda to achieve better outcomes for the care of older Australians. Four broad issues were identified – consumer rights; quality of care; workforce planning; and short- and long-term financing of aged care.

Having watched with some frustration the failure to achieve major reforms and, despite NACA’s existence, the fragmentation of voices calling for change, COTA took to NACA early in 2009 the proposal that NACA develop a ‘new vision for aged care’.

NACA responded positively and in September 2009 published Leading the Way.

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Our Vision for Support and Care of Older Australians, which articulated a vision where ‘every older Australian is able to live with dignity and independence in a place of their choosing with a choice of appropriate and affordable support and care services as and when they need them.’

The ‘NACA Vision’ set out a comprehensive framework for aged care reform within a broader framework of public policies and services to create age friendly communities. Within its aged care specific proposals it importantly called for:

- funding for care and support services linked to each recipient so that the recipient and their family can determine how and where they receive their care and support, including the option to control how their funding entitlement is used;
- funding provided to individuals as an entitlement based on assessed needs, rather than being subject to quotas; and
- funding for care and support based on regularly updated independent benchmarking of the cost of providing care and support in an environment where recipients have full choice of such services.

In June 2009 the National Health and Hospitals Reform Commission delivered its final report to the Rudd Government. While aged care was only a small part of that report the recommendations were substantially consistent with the NACA Vision. The former Prime Minister’s response to pressure to implement those recommendations was to set up the Productivity Commission Inquiry into Caring for Older Australians. CoTA and other NACA leaders successfully pushed for its terms of reference to be broad, encompassing the elements of the NACA Vision. I will not recount the extensive process of the Productivity Commission (PC) Inquiry. It attracted 487 submissions and then 438 more in response to its draft report. COTA’s main submission presented detailed proposals for a new aged care system, many of which found their way into the PC’s final report. We wrote:

‘We are proposing fundamental change that puts individual people at the centre of the system and attaches funding to them rather than to service providers. Individuals would have an entitlement to funding to meet their assessed needs and have more control over what type of services they use and who provides them. This in turn should lead to a more responsive system that meets older people’s changing needs in a more flexible and timely way.’

The Caring for Older Australians final report laid out a blueprint for a new aged care system based on an entitlement, without rationing, a new Gateway to access information, assessment and services and much greater access to home care.
The *Caring for Older Australians* final report laid out a blueprint for a new aged care system based on an entitlement, without rationing, a new Gateway to access information, assessment and services and much greater access to home care.

The Government spent many months reviewing and consulting on the PC report. COTA undertook a substantial consultative exercise aimed at consumers through some 32 ‘Conversations on Ageing’ around Australia, all but four attended by then Minister for Health and Ageing the Hon Mark Butler MP. FECCA was closely involved in helping promote those events to its constituents, as did a range of other consumer bodies and networks. More than 3,400 people attended the Conversations which attracted from 40 to 250 participants each.

The other arm of the Government’s consultation process was undertaken through NACA, and COTA provided much of the secretariat for this process which resulted in a series of reform papers providing advice on the Gateway, Access and Consumer Protections, Workforce, Carers, Dementia, Entitlement and Greater Choice, Health Reform and Aged Care, and Paying for Aged Care (see www.naca.org.au).

Getting the Gillard Government to sign off on aged care reform in the 2012 Federal Budget was not an easy thing. There were many reforms in process or in the wings, including the National Disability Insurance Scheme. Aged care reform has never been a high priority for Labor Governments. Through NACA we ran the Australians Deserve to Age Well (Age Well) campaign to generate community and media support, to which COTA contributed substantial financial and personnel support. Age Well was based around the NACA Blueprint for Aged Care Reform which supported many of the PC proposals, with some compromises for providers.

Outside the NACA campaign COTA ran a persistent and focused campaign of its own to convince the Government that 2012 was not only possible but imperative. Achieving reform in aged care is a tricky business given the political and economic immaturity of much of the sector, the expectation of many in the Government that aged care reform would not pay off politically, and the fiscal pressures on the budget.

In April 2012 the Government released *Living Longer Living Better (LLLB)*, its package of responses to the PC Report. LLLB delivered a game more than doubling of home care packages, the Gateway, extra support for dementia care, making consumer directed care the norm, a national assessment framework and process, an independent aged care financing authority, quality indicators for residential care, a new national home support program, a workforce supplement to leverage wage increases over time, choice of payment in residential care and a uniform user fees regime based on objective criteria.

LLLB did not give us entitlement and an end to rationing. However it increased the ratio of packages and beds from 113 per 1000 people over 70 to 125 per 1000. A review in 2016–17 will consider whether it is time to introduce entitlement and end rationing.

COTA endorsed LLLB and criticised it at the same time. We have stuck to the deals we did with other players in the sector, even when provider groups have breached them. Today LLLB is being implemented through the most extensive consultative process the sector has ever had with the former Department of Health and Ageing and now with the new Department of Social Services. COTA is providing the secretariat for that process on behalf of NACA, work FECCA is fully involved with.
Accessing the Aged Care System: the Aged Care Gateway

Mr Bruce Shaw

Bruce Shaw is the FECCA Senior Aged Care Policy Officer – Reforms. He has a long involvement in health and aged care with a range of organisations including the former Aged Care Association Australia (ACAA), Palliative Care Australia (PCA), the Australian Medical Association (AMA), UnitingCare Australia (UA), Merck Sharp & Dohme Australia, and the Consumers’ Health Forum of Australia (CHF). Bruce has a Master of Public Policy from the ANU and a Bachelor of Arts from the University of Queensland.

In response to the complexity of the aged care system and the difficulty in navigating it, the former Australian Government launched the Aged Care Gateway on 1 July 2013 as a point of entry into the aged care system.

The Gateway’s proposed scope of activities in the short and long term is extensive and includes:

- information on services, fees and quality indicators;
- a national contact centre (1800 200 422, open 8am to 8pm locally on weekdays and 10am to 2pm locally on Saturdays);
- the My Aged Care website (www.myagedcare.gov.au);
- referrals;
- consumer and carer assessments;
- means testing; and
- linking services to vulnerable older people.

A key challenge remains to integrate culturally and linguistically diverse (CALD) perspectives into the overall aged care and health delivery frameworks so that ageing and aged people from CALD backgrounds have access to and equity in using the full range of appropriate aged care services and are empowered and confident in accessing those services.

Given that nearly one quarter of older Australians are from CALD backgrounds, FECCA has strongly argued that the Gateway needs to systemically build in the capacity to deal with CALD consumers.

In response, the former Australian Government Department of Health and Ageing (DoHA) acknowledged that communication difficulties and lack of appropriate information are the greatest barriers for CALD people in accessing the aged care system.

DoHA developed an Access Strategy for People with Special Needs and a Translation Strategy. These were the former Department’s strategic responses in seeking to ensure the accessibility of the Gateway and the whole aged care system for people from CALD backgrounds.

The My Aged Care website currently provides translations of information in seven community languages. The former Department, in the rush

Given that nearly one quarter of older Australians are from CALD backgrounds, FECCA has strongly argued that the Gateway needs to systemically build in the capacity to deal with CALD consumers.
to ensure that the Gateway could commence operations on 1 July 2013, arranged for these initial seven translations of Gateway website information to be professionally translated.

Feedback indicates that some of these translations contain stilted language, at times words and phrases that have not been translated accurately in the aged care context and therefore make no sense, and use of professional jargon. As suggested by this feedback, there are levels of complexity that must be considered in seeking and checking translations. We are pleased by assurances that these problems are being rectified, and will not occur in future. There has also been a commitment that more languages will be added to the initial list of seven, and some debate within the CALD community as to the order in which they should be introduced.

With regard to interpreting services, FECCA commended the decision for the former Department to enter into a contract with the Translating and Interpreting Services (TIS), a real time interpreting service run by the former Department of Immigration and Citizenship. Consequently, clients wishing to speak and be understood in their first language can access My Aged Care and other Gateway information from TIS directly on 131 450. TIS covers more than 100 languages and is available 24 hours a day, 7 days a week, for the cost of a local call. Another option for people needing language support is to call the Gateway Contact Centre on 1800 200 422 which can organise interpreters through TIS to facilitate conversations between Gateway staff and clients.

We look forward to seeing continuous improvement in the Gateway’s services for CALD Australians.

While the Gateway is not perfect yet, FECCA commends the former Department for its work on the Gateway, particularly in relation to implementing these welcome language initiatives.

FECCA is also advocating that the Gateway operations should access and retain ethnicity data on people accessing it, in order to identify any underrepresented communities and unmet need.

As this magazine goes to press, the composition of the first Abbott Ministry has just been announced. It appears that all ageing and aged care policy and program responsibility has been transferred from the former DoHA to a new Department of Social Services. It is uncertain at this point how this change will impact the CALD Aged Care sector.

FECCA hopes that advances such as the TIS contract that have been achieved will be maintained, and the promised further improvements as part of the aged care reform process will be honoured. We look forward to seeing continuous improvement in the Gateway’s services for CALD Australians.

FECCA is actively advocating on these and other key issues in relation to the ability of people from CALD backgrounds to access to the aged care system. Continuous lobbying will be necessary to ensure that true access and equity are achieved.
Healthy, Active Older Australians:
A social and economic imperative

Ms Mary Patetsos

Ms Mary Patetsos is Chair of the FECCA Healthy Ageing Reference Committee, a member of the Multicultural Communities Council of SA and a Board Member of Aged Care Housing (ACH) Group. At the federal level she is a member of the Aged Care Financing Authority as well as on the National Housing Supply Council. She has a passion for housing as well as working in aged care and is currently Deputy Chair of the South Australian Housing Trust and Deputy Chair of Common Ground Adelaide. Mary has worked for many years at senior levels of the Government and the community sector and actively pursues policy and practice that connects and nurtures partnerships, innovation and collaboration across sectors.

The demographic picture is clear. According to the 2011 census there is an increase both in the total numbers and in the diversity of languages other than English spoken at home for the 65 plus age group. There is an imperative to focus on how to ensure healthy ageing for this group and to have an aged care sector with the capacity to serve and care for them.

As the Living Longer Living Better reforms are rolled out there has been an enormous focus on system improvements, ranging from Aged Care Gateway access to new funding arrangements. The need for these reforms has been both timely and necessary as they aim to create a more accessible and consumer driven service model focused on the sustainable growth of the sector and higher quality care. The reforms are shaped to create an environment for greater consumer control, integration and innovation. They do this not by demanding change but by encouraging, prompting and building the capacity of all Australians as they get older to live life to the fullest.

These systemic reforms also tackle the challenge of an increasingly diverse population in terms of income, ethnicity, language and sexual orientation. As Chair of FECCA’s Healthy Ageing Reference Committee I have often asked the question, ‘how is all that we are doing making life better, healthier and more fun for older Australians of culturally and linguistically diverse (CALD) backgrounds?’

I am curious to know how much of what we have done so far has improved life for frailer older people as well as adding meaning and purpose to those years that our extended life expectancy offers us. Specifically, I want to know what the ingredients for a healthy and good life are for older people from CALD backgrounds. The most logical paradigm of care is one that places community engagement, positive self-esteem and a sense of worth at its centre.

Older Australians are an active part of our community for many years but then, slowly, they withdraw from active engagement due to a loss of meaningful roles. They are experienced, capable and competent and in a global economy the continued engagement of this group makes economic sense. They are a reliable, able workforce at a time when our businesses need capability and experience. They are active consumers, volunteers and unpaid support to families as carers of children, particularly in two-income families. So what happens that disengages older people from CALD backgrounds from meaningful roles in community?

The primary shift is an early exit from paid employment through retirement, the burden of housing that is no longer ‘best fit’ nor ‘fit for purpose’ and slowly a loss of employment currency especially in labour intensive industries.
The challenge for us is to execute a reform process that encourages new roles for such people as they exit their first career in ways that suit them and that provide and facilitate an engagement in work that is tailored to each individual. Their new roles may look different to their previous ones. They may be part-time and they may work from home, trading security of employment and salary for flexibility. Enhancing an individual older person’s sense of self-worth through engagement in meaningful roles, including paid and unpaid work, is a key challenge.

We also need to focus on positive self-esteem and building older Australians’ sense of worth. While this is not hard to articulate as an aspirational goal it is the greatest challenge to achieve. How do we shift community attitudes towards CALD older people from that of ‘sitting in God’s waiting room’ to a perception of them as a vibrant, engaged population cohort which contributes to the economy and to their community? Like most things in life I suspect that this will take action, experience, affirming role models, positive media images and real life examples to breakdown stereotypes. For example, nothing is better to teach young women more about their worth than to see other women perform meaningful roles. This will be the case as older people are encouraged and rewarded to stay connected. Their impact on the economy, culture and community will be told through example. So the challenge is to enable this connection, promote engagement and to facilitate the creation of new roles for older Australians, not because they are old but because they have so much to give and we have so much to gain and benefit from them.

Inevitably, some older people from CALD backgrounds will engage with the health and aged care system because of their physical frailty and ill health. It is then that we need to have a robust service system that meets their needs with respect and dignity. So let’s keep on working on the Living Longer Living Better reforms. Simultaneously and perhaps with greater urgency let us also remember that the challenge to find purpose and meaning in life lies in those years before they need care. Intergenerational links and flexible participation in community and work provide the clues on how to achieve change. Striving to activate older people will unlock their potential to live good lives and this will, in turn, build on and capture the value that lies in their hearts, hands and minds.

The challenge for us all is to disentangle ageing from the welfare web. To achieve this we need to foster partnerships with Government, other stakeholders and importantly, with older people. Not just for their sake, but for our own. For those of us who work in the area we need to innovate and create new pathways of engagement with older Australians. ■
Delivering Culturally Appropriate Aged Care to All Australians

Ms Elaine Goddard

Ms Elaine Goddard is UnitingCare Ageing’s Community Operations Manager (West South), a position that involves overseeing the delivery and expansion of the organisation’s community care services to clients throughout south-western Sydney and southern NSW.

In 2012 Elaine represented UnitingCare Ageing on the Australian Government Department of Health and Ageing Working Party that developed the framework for the Australian Government’s National Ageing and Aged Care Strategy for People from CALD Backgrounds.

Originally from England, she came to Australia in 1969 with her family as part of an assisted immigration program, and settled in Sydney.

Elaine is passionate about social justice issues and supporting people who, for whatever reason, are marginalised in society. She has a special interest in working with people and groups from different cultural backgrounds and in recent years has formed many partnerships and relationships with CALD groups across western Sydney.

People from culturally and linguistically diverse (CALD) backgrounds make up a significant and growing proportion of Australia’s older population.

In 2011, 20 per cent of Australians aged 65 and over were from CALD backgrounds. Forecasts estimate that this proportion will increase to 30 per cent by 2021.

There is significant diversity within the older population of CALD communities in terms of nationality, religion, culture, language, educational background and socio-economic status. This is partly attributable to changes in Australia’s post-war immigration policies.

For example, at the moment, immigrants from non-English speaking European countries (Italy, Greece, Germany and the Netherlands) make up a higher proportion of the CALD aged community than immigrants from other parts of the world.

However, in coming years the proportion of older Asian immigrants (particularly from China, Vietnam, India and the Philippines) will increase, while the number of CALD seniors from non-English speaking European countries is expected to decrease. This will reflect Australia’s greater focus on Asian immigration during recent decades.

In Australia, CALD seniors are among certain groups of people who are recognised in legislation as having special needs when it comes to planning and delivering aged care services. An obvious example is the need to provide appropriate care and services for seniors with limited English language skills.

This special needs classification reflects the importance the Government places on delivering culturally appropriate aged care to all Australians. It also reflects the fact that as a group CALD seniors historically have faced difficulties when it comes to accessing appropriate aged care services. Simple examples include a lack of cultural inclusiveness by some aged care providers, and communication problems exacerbated by a lack of bilingual staff and volunteers.

The Australian Government has established various programs to help ensure that the aged care needs of CALD seniors are met. Organisations that promote wide access to
aged care information and services for CALD communities are being encouraged.

UnitingCare Ageing is the arm of the Uniting Church that is the church’s ministry to older people, particularly those who are disadvantaged, vulnerable or isolated. It operates community care services, independent living accommodation and residential aged care facilities throughout NSW and the ACT.

One of UnitingCare Ageing’s core values is respect – as an organisation we actively endeavour to honour all people, value diversity and uphold dignity. One practical way we have ‘lived out’ this value as an organisation has been to embrace opportunities to link and partner with various CALD aged communities.

Our partnership with an Indian Sri Lankan community in western Sydney helps highlight the way we operate with CALD groups. This partnership, which has been in place for five years, involves UnitingCare Ageing, Grantham Heights Uniting Church (Seven Hills) and Sri Om Care (a not-for-profit Indian Sri Lankan welfare group).

UnitingCare Ageing was approached in 2008 by Sri Om Care to assist in establishing a day program for their community. Prior to this, UnitingCare Ageing had already been engaged in talks with the Grantham Heights congregation about how to partner and address local community needs. After several meetings to discuss potential opportunities, in late 2008 a partnership was developed with Sri Om and the congregation, which included the use of the church hall as a venue for the Sri Om day program. Very quickly the congregation and Sri Om became well acquainted and joint activities and celebrations began.

Initially there was no funding for the program, so UnitingCare Ageing provided the program as a social justice initiative. This continued until 2011, when funding was secured. The program now runs every Friday and is based on the Healthy Living for Seniors model, which is an enabling restorative approach leading to empowerment of each person – developing individuals’ strengths and abilities.

The day program gives people who attend the opportunity to participate in exercise.
programs, meditation, and to cook and share a meal they enjoy. Importantly, it provides an opportunity to socialise with peers and have a regular meeting place in a safe, secure, positive environment. Volunteers from the church offer support and some join in activities.

Many of the participants came to Australia to assist their children with child-minding so their children could work or study. Many cannot drive and although they have excellent English skills they have never worked other than in the family home. Having no independent income or transport can be quite isolating within the larger community.

Attendees have praised the program, which has helped them to feel valued and connected to their community. One said: ‘We just want to come together in a safe place and do things we want to do, not what other people want us to do.’

UnitingCare Ageing has formed many close links with CALD aged communities across NSW and the ACT. In each community the focus is on building collaborative partnerships, supporting informed decision making and developing culturally appropriate ways to address needs. As an organisation, we listen to community needs and then partner with communities using a community development approach.

To find out more about our services please visit www.unitingcareageing.org.au. We are always looking at new ways to work and new partnerships. If you have any thoughts, ideas or questions, please write to me via egoddard@unitingcarenswact.org.au.

**Some facts and figures**

UnitingCare Ageing is actively developing partnerships with culturally and linguistically diverse (CALD) communities across NSW and ACT to ensure their elders are able to live the lives they want.

UnitingCare Ageing currently operates services to elders from 37 different CALD backgrounds.

While as an organisation UnitingCare Ageing seeks to provide culturally appropriate care across all its services, it operates 24 community and residential aged care services that specialise in providing care to CALD communities. These services operate mainly in Greater Sydney, but others also operate in Queanbeyan and on the Central Coast of NSW.

Other initiatives to help meet the needs of CALD aged communities include:

- the establishment of partnerships and referral points with CALD community organisations;
- the use of culturally appropriate assessments, involving trained interpreters and access to advocates, to ensure care plans include culturally appropriate goals and interventions including incorporating cultural/religious festivals;
- recruitment of a diverse workforce and the provision of cultural competency training;
- ensuring the availability of translated information in a number of different languages;
- the use of life story books to reflect on a person’s culture, religion and traditions;
- facilitating people to maintain links with their communities to reduce social isolation and depression; and
- early referral to diagnose dementia as most people with dementia from CALD backgrounds are diagnosed later and often during crisis.
I’ll Have CALD With That...

Ms Rosa Colanero

Rosa Colanero was educated in SA with degrees and postgraduate qualifications in Arts and Education from Adelaide University; she also undertook postgraduate studies at Rome and Perugia Universities in Italy. Rosa has worked as a teacher in the secondary and tertiary sectors in SA and internationally and also worked in education administration and in the teacher professional development area for many years. She has extensive experience in policy, information and resources development and training, and programs and projects development and implementation. She has chaired and sat on numerous ministerial committees and peak bodies focusing on education and training, gender issues, access and equity and social justice, cultural diversity and community capacity building.

Rosa is currently Chief Executive Officer of Multicultural Aged Care Inc (MAC) which delivers information, resources and training in the aged and community care sector so that service providers can better deliver culturally appropriate care and older people from diverse cultural and linguistic backgrounds can receive targeted and culturally inclusive information and services.

Multicultural Aged Care Inc. (MAC) in SA has been delivering aged and community care programs and projects focusing on culturally and linguistically diverse (CALD) aged and community care information, resources and training for 20 years.

MAC initially auspiced programs and then transitioned them to CALD community groups to strengthen their capacity to deliver services to their older people, and supported Home and Community Care (HACC)-funded CALD agencies to deliver responsive, accountable and better practice services. MAC has also successfully administered the Partners in Culturally Appropriate Care (PICAC) program in SA for 16 years and (formerly) Community Partners Program (CPP) in SA for 8 years. During this time we have seen that:

- more aged care services can deliver culturally appropriate care to older people from CALD community groups;
- older people from CALD community groups have increased access to culturally appropriate residential and community care services including aged care support services; and
- older people from CALD community groups have greater capacity to make informed decisions about residential and community based aged care.

These three aspects are the PICAC Program Outcomes, which are continuing to be met by the seven PICAC programs around Australia. These PICAC programs are the CALD aged and community care technical experts and although working within modest budgets, the PICACs have punched way above their weight. Their state and national innovations and achievements are outstanding.

PICACs foster access to culturally appropriate aged and community care information and services; facilitate links, network and build partnerships among CALD community groups and service providers; promote and deliver cultural competency training; and develop leading edge resources (online and hardcopy) so that aged and community care service providers have access to validated materials.
Through the PICACs, (previously) CPP and specifically targeted CALD HACC programs and services, it is evident that an increasing number of older CALD persons are receiving targeted and responsive aged and community information, care and services. This is because, with the right support, CALD community groups are delivering better services to their older people and aged and community care service providers are delivering culturally responsive information and services.

PICACs have reviewed and analysed trends, gaps and challenges in the CALD aged and community care sector and although some programs are working well for some individuals and groups, others continue to face barriers and marginalisation.

Over the years, through extensive engagement with CALD groups and service providers through networks, forums and conferences, MAC has identified and set priorities for addressing a number of barriers experienced by CALD community groups. Barriers experienced by CALD older people include:

- care providers presuming culturally specific concepts and meanings of ageing, aged and community care services;
- declining English language proficiency;
- reverting to primary languages and cultures;
- growing reliance on family and known group/community;
- declining cognitive abilities, health and mobility;
- preferring to access or receive culturally responsive information and services in specific languages other than English (LOTE) formats, timelines and settings;
- preferring to access some services provided by family and trusted, specific community groups, in the home or known community; and
- understanding communication from services as formal and bureaucratic, particularly through the internet and written word.

Due to these and other barriers, some CALD older people are not engaging with ageing and aged and community services. They express a need for information and services from people they know and trust and in settings, formats and timelines that recognise their cultural interests and concerns.

Some of the current generalist aged care programs are not addressing the breadth, depth and specificity of the identified needs. There is a need for more responsive and targeted funding to specific CALD groups for these programs. There is also a need for a more coordinated and informed approach to promoting information pathways, resources and training to address the ageing and aged and community care needs of CALD older people.

This approach must be multi-faceted and include cultural awareness/competency training for the ageing and aged and community care workforce, culturally appropriate resources that are targeted toward specific groups. These groups should include service, workforce and training providers as well as specific CALD community groups and their older people.

MAC has worked collaboratively with a number of service providers to promote diverse models of service provision, including clusters, ethno-specific, multicultural and generalist aged care services. These models are promoted for existing and new services, taking into account learnings garnered from past experiences and analysis. MAC proposes that future developments and improvements for existing and new services consider:

- responding to demographic profiles, specific foci, priorities and economies of scale;
- encouraging CALD-inclusive forward planning;
- developing shared understandings of timelines and timeliness;
- building up trust and cultural competencies;
- foreseeing and factoring into planning that raising awareness may not progress to gaining acceptance; and
- continuing to recognise, respect and respond to the special and specific needs of CALD older people in the management and delivery of clinical aged and community care and services.

In considering these trends, gaps and challenges, MAC, in collaboration with other PICACs, has outlined a number of strategies, outcomes and outputs for better practice.
culturally appropriate care. Key priorities include:
- incorporating CALD perspectives in the planning, policies and practices of information and services provision;
- ensuring processes of communication are targeted, responsive and in formats and settings appropriate for CALD older people; and
- the provision of training for people and service providers to deliver culturally responsive and competent information and services.

Older people from CALD community groups are more likely to access and receive better practice culturally appropriate aged and community care services when the planning, policies, procedures, programs, processes and practices are inclusive of diverse cultural and linguistic perspectives.

At the heart of the work of the PICAC programs is a Cultural Intelligence (CQ) framework that serves as a cultural competency model in the sector. This framework recognises four key factors that enable aged and community care service providers to develop and demonstrate competencies in living and working in a culturally diverse society, community and work environment. The ‘four As’ of this framework are:
- acquiring cultural experiences, knowledge and understandings;
- applying cultural content factors to knowledge, skills and competencies;
- adjusting behaviours – being mindful of cultural content and checking assumptions; and
- anticipating knowledge, skills and competencies to be effective in intercultural settings.

Promoting the value of this Cultural Intelligence (CQ) framework as a cultural competency model in the sector will enable MAC and the PICACs to achieve better coordination between service providers and CALD community groups, and ultimately the increased delivery of better practice culturally appropriate care to older people from CALD backgrounds.
Dementia Friendly Communities and Organisations

Mr Glenn Rees AM

Mr Glenn Rees AM, CEO Alzheimer’s Australia, has worked at senior levels in the British and Australian Public Services. In Britain he worked as Private Secretary to senior Ministers, in the Cabinet Office and in Economic Departments. In Australia since 1976 he has worked in program and policy areas including Prime Minister and Cabinet, Employment and Training, Aged Care, Disabilities, Housing and the Aboriginal and Torres Strait Islander Commission. He was Chair of the Nursing Homes and Hostels Review in 1986 and was involved in implementing the first wave of aged care reforms. He has been CEO of Alzheimer’s Australia since 2000, during which time the Dementia Initiative was implemented in 2005 and important commitments made to tackle dementia in the 2012 Living Longer Living Better package. He is an active member of the National Aged Care Alliance and has been a member of many ministerial and official advisory committees on aged care.

Dementia is a substantial health issue, with the total number of people living with dementia in 2010 estimated at over 35 million globally by the World Health Organisation. Here in Australia, the disease currently represents the leading cause of disability in people aged 65 and over, with in excess of over 321,600 people living with dementia. These figures are set to increase dramatically, with the number expected to rise to nearly 1 million in Australia by 2050.

Although the increasing number of people living with dementia has raised awareness of the disease in the broader community, dementia still remains to a large extent misunderstood. Numerous misconceptions about dementia abound, including the view that dementia and forgetfulness are a normal part of ageing. Fear of diagnosis is also common; in a large scale study conducted in five countries (United States, France, Germany, Spain and Poland) Alzheimer’s disease was the second biggest fear after cancer in four countries. The lack of understanding and fear of developing dementia leads to stigma, avoidance or discrimination which subsequently results in social isolation of the person with dementia and their carer.

In Australia, the proportion of older people from culturally and linguistically diverse (CALD) backgrounds is significant with one in eight Australians with dementia not speaking English at home. The experience of dementia in CALD communities varies greatly with many members of CALD communities not sharing the Western view of dementia. Dementia may be viewed as a normal part of ageing or seen as a mental illness or ‘madness’. This lack of understanding and awareness of dementia is frequently compounded by language barriers; the term dementia may have different meanings in different languages. This often results in a delayed diagnosis of dementia which results in considerable distress and confusion for the person living with dementia and their family members.

Problems accessing information and services for CALD communities also poses a considerable problem and can arise for a number of reasons, including:

- similar or equivalent services are unavailable in their country of origin, thus resulting in a lack of awareness about services or expectations about service provision;

- minimal resources available that are relevant to their community;
• feelings of shame, embarrassment or reluctance to acknowledge dementia may result in the person or their family not seeking assistance;
• language barriers which makes initiating contact and traversing the system problematic;
• feelings of discomfort in accessing mainstream services; and
• cultural expectations for family members to contend with problems rather than contacting outside services.

The concept of Dementia Friendly Communities and Organisations has gained popularity around the world in recent years. Dementia Friendly Communities, defined here as ‘...a cohesive system of support that recognises the experiences of the person with dementia and best provides assistance for the person to remain engaged in everyday life in a meaningful way’, offers support for the person living with dementia and their carer and also promotes awareness and reduces the social isolation and stigma that regularly follows a diagnosis of dementia.

Initiatives aimed at supporting the person with dementia to remain engaged in everyday life are divided into two separate areas:
• social environment which encompasses community and support services, employment, social inclusion and stigma; and
• physical environment which includes the tangible aspects of the environment such as land, buildings, public spaces, housing and transportation.

Developing a program to encourage dementia friendly communities and organisations only makes sense if it is done in collaboration with people with dementia.

To address the stigma and social isolation experienced by people with dementia and their families it is necessary for Australia to adopt Dementia Friendly Communities and Organisations. This is particularly important in CALD communities who experience considerable social isolation and barriers due to cultural and language differences.

A number of communities in Australia are already doing a magnificent job of promoting social inclusion. These include education programs for CALD carers, dementia choirs, memory cafes, walking groups, Men’s Sheds, and countless other activities. Alzheimer’s Australia has also developed a DVD entitled It’s not a disgrace – it’s dementia for eight communities. The DVDs feature health professionals and families of a given culture discussing dementia and encouraging their fellow community members to recognise the disease and not be fearful or ashamed of a diagnosis of dementia.

Alzheimer’s Australia will be working this year to develop a national recognition program for dementia friendly communities and organisations. The concept will be to encourage communities and organisations to begin a process of self-audit, in collaboration with people who have dementia, to identify potential areas for improvement in awareness, information, physical environment and social inclusion. We will not be endorsing particular approaches, but instead recognising organisations and communities that are working to improve their services and environment for people with dementia. The program will also support organisations in this work through provision of resources and information.

Developing a program to encourage dementia friendly communities and organisations only makes sense if it is done in collaboration with people with dementia. We will be working closely with our national consumer advisory groups (National Cross Cultural Dementia Network, National Aboriginal and Torres Strait Islander Dementia Advisory Group, National Consumer Advisory Committee) including the new dementia advisory group, which will be made up of people with dementia, on the development of resources and guidelines. We are hopeful that this approach to dementia inclusive society in Australia.

For a full list of references, please contact Dr Ellen Skladzien: ellen.skladzien@alzheimers.org.au
Friend and Family Carers of Culturally and Linguistically Diverse Australians – Access to Carer Supports

Ms Ara Cresswell

Ms Ara Cresswell is the CEO of Carers Australia and recognises the community sector is at the heart of a deliberative democracy. Ara believes that carers should have their voices heard and considered across every aspect of public policy, government engagement and community service delivery. Ara has long-term experience as an advocate in the community sector, having held senior roles at Reconciliation Australia, the ACT Council of Social Service, the Australian Federation of Homelessness Organisations (now Homelessness Australia), and Toora Women Incorporated. Ara says that in our lifetimes each one of us is likely to either be or need a carer, so taking care of carers is really about taking care of our families, our friends and ourselves.

Carers provide unpaid care and support to family members and friends who have a disability, mental illness, chronic condition, terminal illness, an alcohol or other drug issue or who are frail aged. The Australian Bureau of Statistics’ Survey of Disability, Ageing and Carers 2009 estimated that there were 2.6 million carers, or 12.1 per cent of the total population, in Australia. Of these, 25 to 30 per cent are from culturally and linguistically diverse (CALD) backgrounds. Of those people aged 65 years or older who identified as having an informal carer, 37.2 per cent were born outside of Australia. Those speaking a language other than English at home numbered some 17 per cent, and 10.4 per cent did not speak English well or at all. Given the ageing population, there is likely to be an increase in the number of CALD carers providing unpaid care to older people.

In addition to cultural and linguistic diversity, CALD carers are diverse in many other ways. They may care for one or more people who are aged, frail and/or who have chronic illness or disabilities. They range from the very young to the very old.

‘Mum has a few different illnesses but she doesn’t speak English very well. I do a lot of the cooking and cleaning and looking after my brothers so it can be hard to find time for school work.’
– Lala, young carer, age 10

In some cases they will be caring for more than one generation. They may have been born in Australia or born overseas. They may be refugees.

Depending on how the person they care for came to Australia and their prior experiences, there will be differences in the physical and mental conditions of those who require care. For example, a recent report based on young carers in receipt of carer income support noted that, where the person the young person cared for had immigrated from an area of ethnic or religious conflict, there was a 30 to 40 per cent likelihood that they were caring for someone with anxiety or depression as the main medical condition. This contrasts with 10.5 per cent of young carers who are Australian-born.

Despite these differences, research into carers of people from CALD backgrounds has identified a number of common problems in accessing carer supports. Indeed, CALD carer access to Commonwealth support programs, other than income support, is usually low – varying from between 8 to 24 per cent of beneficiaries. There are a number of reasons for this.

Firstly, people from CALD backgrounds may not identify as carers because the term has no particular cultural meaning for them. It is simply a natural part of their cultural obligations...
Even where people are aware that carer supports are available, they may be unlikely to use them for a variety of reasons. For example, certain cultural groups may be opposed to the idea of carer support groups and discussing family business with others, especially where there is a stigma regarding certain health conditions or disabilities.

and the English equivalent of words like “carer” or “respite” or “hospice” may have no translatable equivalents in their own languages. Obviously, if you don’t identify as a carer you are unlikely to seek formal support – especially if there is a paucity of information in your own language.

Even where people are aware that carer supports are available, they may be unlikely to use them for a variety of reasons. For example, certain cultural groups may be opposed to the idea of carer support groups and discussing family business with others, especially where there is a stigma regarding certain health conditions or disabilities.

In other cases, previous negative experiences or concerns about the cultural appropriateness of services may discourage CALD carers from seeking help. They may have concerns about the provision of culturally acceptable foods, the presence of bilingual staff and whether the gender of staff members will be matched to the gender of the consumer.

In other cases, there may be simply no suitable service available. One particular problem is the lack of services for small or emerging CALD communities in both urban and geographically remote areas.

The evidence suggests that there is no single model of service provision that meets all the needs of CALD carers and that there is a need for choice between mainstream, multicultural and ethno-specific providers.

Partnership with other community organisations catering specifically for CALD communities probably works best, but requires adequate long-term funding as well as good access to information and educational material. There is also strong evidence to support consumer directed respite (where consumers have a level of choice of service provider and control of funding) and host home respite (small groups of people with care and support needs within a paid carer’s home) for CALD carers.

‘It’s very hard to find information for CALD people. Mostly, we find information from this [Korean] carers’ group.’

– Korean carer at a forum convened by Carers Australia

There is a pressing need for further research to identify best practice to better inform Government policy and programs.

The network of State and Territory associations affiliated with Carers Australia assist CALD carers through a variety of avenues. Carers ACT, Carers WA, and Carers NT have stand-alone CALD carer programs with coordinators and native language support groups. Carers VIC, Carers NSW and Carers SA have long-standing collaborations with ethno-specific and multicultural organisations to assist CALD carers. Carers TAS has recently developed a Diversity Project. Carers Australia associations offer translated information and can arrange for some interpreted services, though this is not sufficiently well-funded to meet demand.

For further information about CALD carers, including a background report, a fact sheet, and an inventory of services, programs and resources for this carer group, visit: http://www.carersaustralia.com.au or call (02) 6122 9900.

Carers Australia is conducting further research into ways to better enable support for CALD carers – please contact us (Jade Taylor jtaylor@carersaustralia.com.au) if you can contribute information.
What CALD Carers Really Need

Ms Anndey Ho

Ms Anndey Ho is the CALD Program Coordinator at Carers ACT. Anndey’s program aims to reach out to carers from culturally and linguistically diverse (CALD) backgrounds, provide support and link them to existing carer services. She has a background in social science, psychology, counselling and special education. She has worked in the government sector as well as the community sector for people with disability. She was involved in a pioneer project with Mental Illness Education ACT (MIEACT) to explore the concept of mental illness among people from CALD backgrounds. She was a committee member of MWA (Multicultural Women’s Advocacy) and currently a member of the ACT Multicultural Mental Health Network (formally known as the Diversity Health Network ACT). Her passion is in CALD aged care and mental health.

Carers ACT (formerly the Carers Association of the ACT) is a well-established peak body for carers in the ACT. It has been operating in the ACT for over 20 years. Historically it was started by a group of carers holding a public meeting to address concerns about the needs of those who are caring for aged people. The ACT Group started six years after the world’s first Carers Association was established in New South Wales. Later, the Carers Group was formed under the auspices of the Council of the Ageing (COTA) ACT to offer counselling and provide an opportunity for carers to meet each other to share and discuss issues and concerns. Subsequently the Group received funding from the Department of Health and Ageing (DoHA) and the Home and Community Care (HACC) program to meet the rapidly increasing demand within the ACT.

Due to the continuous support and funding from both Commonwealth and State Governments, Carers ACT continues to grow and develop many specialised programs to provide support and services to carers living in the ACT. Our programs aim to ensure carers have access to appropriate services and support as well as to maintain their wellbeing. The Culturally and Linguistically Diverse Program (CALD Program) is one of our many programs which aims to provide support and services for carers from a wide range of diverse backgrounds.

In 2004, Carers ACT recognised that there are many ‘hidden carers’ who do not see themselves as carers. Hidden carers view their caring role – providing care as a wife, husband, sibling, or even a friend – as a normal part of life. They will be the last to identify themselves as carers and are often left isolated and without support. Carers from CALD backgrounds often fall into this description. Carers ACT took the initiative to conduct a consultation with the greater CALD community. We identified that one of the enduring barriers for CALD carers is language. In response to this need, 15 support groups were established with their own bilingual community facilitator to provide support in their own languages. The groups provide the opportunity for CALD carers to receive information and share and discuss their own issues and concerns in their own languages. The CALD Program continues to provide the first point of contact for carers to learn about and access services available in the ACT. Through continuous support, the CALD Program can assist CALD carers to identify their needs and navigate carer services.

Carer ACT also recognises that CALD carers are
disadvantaged by their language barrier in recognising or understanding any new changes to policies or service delivery which might impact upon their caring roles. Therefore we regularly provide updates and remind them about new changes or reforms in carer services. In the past 12 months, the CALD Program has conducted information sessions on the changes to existing carer services and reforms to the aged care system. Through this process, we have identified a few gaps and issues that CALD carers are experiencing and which are hindering their access to both the existing and new services.

We identified that most of the existing carers who are attending CALD support groups are not aware of the new aged care reforms. Even those who have heard about such reforms via the media or friends, still encounter difficulties in understanding the scope of service and how the changes apply to them. In a recent interview, General Peter Cosgrove (the former Chief of the Australian Defence Force, current Chair of Leading Age Services Australia) commented on aged care in Australia, who explained that Australia’s rapid ageing population is causing hospital beds and aged care facilities to fill up. Due to this increased longevity, parents could soon be joined by their own children in aged care facilities.

CALD carers are already facing this challenge. Many CALD carers are expected due to cultural norms to care for their elderly parents at home as long as they can. Many of our known CALD carers have reached 65 years and over, they are still caring for their frail parents who are in their late 80s. Services required to support both of them can be complex and even more costly than residential care.

Part of our CALD Program is to provide individual support and assistance to these people and link them to appropriate care services.

Due to different cultural practices, CALD families will take a decision to engage external help very solemnly and seriously. They might only use respite services when they have run out of all other options. In order to assist CALD carers to recognise the importance of their own well-being, we gradually encourage them to open up to the idea of using some form of respite such as domestic assistance or social support. On the other hand, language barriers are often a hindrance for CALD families in seeking support. Even though service providers encourage CALD carers and families to use Telephone Carers at the Carers ACT 2012 Open Day, an annual event which celebrates carers’ contribution to the community.
Interpreting Services (TIS) National to assist them when there is no bilingual worker available, there are limitations in terms of practicality, especially during a home care visit. One of the methods we can use to assist the family and the service provider is to arrange ‘flash cards’ (translation of commonly used terms) to facilitate basic communication between the care worker and the recipient. All these can happen because of the efforts of both the CALD Program coordinator and the Bilingual Community Facilitator (BCF).

Carers ACT also understands that CALD carers often encounter difficulty in navigating and understanding the medical system in Australia. This experience does not only apply to CALD carers with language barriers. Carers with adequate language skills can also encounter difficulties due to the stress of being overwhelmed with caring responsibilities, combined with the complexity of our medical system compared to what they may have been used to in their home country. Hospital and residential care facilities do engage interpreters to facilitate communication when they identify the need for language assistance, however interpreters cannot advocate for carers. Our bilingual workers can act as ‘extra ears’ during family meetings, help facilitate communication, assist carers to explore available options, as well as just be there to provide comfort beyond words.

The National Ageing and Aged Care Strategy for People from Culturally and Linguistically Diverse (CALD) Backgrounds is designed to inform the way Government supports the aged care sector to deliver care that is appropriate and sensitive to the needs of older people from CALD backgrounds. The Strategic Goals of the Strategy list many actions which need to be addressed such as promoting information about Home Support and Home Care to CALD communities, and improving interpreting and translation services.

The Carers ACT CALD Program has already established a good framework to provide services to people from diverse backgrounds. We have already established and built up good rapport amongst CALD community members in the ACT. The strong community response to this and other programs that focus on personal support for carers indicates that such programs should not only be afforded ongoing financial support, but also highlighted throughout the implementation of the Strategy as good-practice models in the provision of care and support to older people and carers from CALD backgrounds.
How Bhutanese Elderly Live in Australia

Mr Parsuram Sharma-Luital JP

Parsuram Shama-Luital JP is a former refugee from Bhutan who arrived in Australia in 2002. He obtained a Master of Horticulture degree from the University of Melbourne in 2004. He is the Chair of FECCA’s New and Emerging Communities Advisory Committee, Board Member of the Ethnic Communities’ Council of Victoria (ECCV) and Convenor of the New and Emerging Communities Policy Committee at ECCV. He is also the Founding and Immediate Past President of the Bhutanese Organisation in Australia. Parsu has represented Australian refugee communities on behalf of the Refugee Council of Australia (RCOA) and has attended UNHCR Standing Committee meetings and NGO Consultations in Geneva annually for the past four years. Parsu worked as a Project Coordinator at AMES for five years, delivering road safety driving projects to newly arrived people from refugee and immigrant backgrounds across Victoria. He currently works at Victoria Police as a New and Emerging Communities Liaison Officer for the North West metro region based in Moonee Ponds.

The Australian Bhutanese are one of the most recently arrived immigrant communities in Australia. The Australian Government, under its Humanitarian Settlement Services (HSS) program, committed to resettle 5000 refugees from Bhutan, beginning in 2008. A large majority were settled in Adelaide, while others live in places as diverse as Albury-Wodonga, Cairns, Hobart, Launceston, Melbourne and Sydney. Many of these former refugees spent 18 to 20 years living in seven refugee camps managed by the United Nations High Commission for Refugees (UNHCR) in southeastern Nepal – in basic huts with earth floors – after they were evicted from Bhutan between 1990 and 1992.

Refugees from Bhutan are ethnically Nepali, known as Nepali-speaking Bhutanese or Lhotsampas (‘people of the south’), and are largely Hindu. The hope of returning back to Bhutan faded after 15 rounds of bilateral talks between Nepal and Bhutan failed. With no possibility of repatriation or local integration in Nepal, third country resettlement was therefore the only durable solution left to address this protracted refugee crisis that has now lasted for more than 20 years. Australia was one of eight countries that agreed to resettle 110,000 Bhutanese refugees. Along with the young and the middle aged also came their elderly parents and grandparents. These older men and women were all landowners and farmers in Bhutan prior to their eviction, and have always lived together with their extended family – three generations in one house. This has changed for some Bhutanese families in Australia, who were divided into smaller units as a part of the resettlement program. However, extended family networks have remained close and provide an important source of strength for newly-arrived Bhutanese in Australia.

The Australian Bhutanese are one of the most recently arrived immigrant communities in Australia. The Australian Government, under its Humanitarian Settlement Services (HSS) program, committed to resettle 5000 refugees from Bhutan, beginning in 2008.
Many resettled seniors and pensioners I have spoken to over the past four years have told me that they prefer immediate family members to accompany them to Centrelink, medical and other appointments. These family members provide crucial support and help mitigate the shock of being in a new country, as well as helping elders overcome obstacles such as the language barrier, lack of understanding of Australian cultural rules and laws and lack of trust of authorities, government agencies and interpreters due to past experiences as refugees.

The concept of living away from family in an aged care facility is completely foreign in the Australian Bhutanese community, and even Home and Community Care (HACC) is accepted only in extreme circumstances.

Upon arrival in Australia, most Bhutanese seniors keep busy and stay connected to their community through two self-initiated activities. As subsistence farmers in Bhutan for generations, they are very connected to the land and spend significant amounts of time growing vegetables in their backyard, just as they used to do in the backyard of their refugee camps in Nepal. They often produce enough food for their entire family and to share with neighbours all year round. Most families do not buy vegetables from the supermarket; only essentials that are not produced in the garden such as meat and

Senior Bhutanese were honoured at the 2012 Melbourne Multicultural Festival by Maria Vamvakinou MP, federal member for Calwell and Andrew Elsbury MLC, member of the Legislative Council for Western Metropolitan Region.
Seniors’ programs exist in some places of resettlement and run for a few hours per week, but most Bhutanese seniors spend much of their time alone at home while their children and grandchildren go to work and school.

Spices. Bhutanese seniors also stay connected to their community by attending Bhajan-Kirtan – regular singing and chanting groups – in rotation among different homes on a weekly basis as well as on religious occasions. Maintaining this connection to the land and spending time with their family is fundamental to living a dignified life and practising their cultural traditions. Aged care facilities cannot offer them this freedom and cultural connection.

For many Bhutanese seniors, losing the ability to contribute to society through work is extremely difficult; they prefer work in any form, such as gardening, unless they are bedridden. One Bhutanese senior resettled in the US said, ‘What do I do? I cannot speak English. I am 56 years old. I cannot go to work, I cannot do anything. I want to work. I want to do what I have been doing all my life. I want to be active. But all I do is stay at home. I have to keep quiet, because I cannot speak English.’ I have heard many Bhutanese seniors say at community consultations with Government agencies and service providers that they would like to be offered jobs – even low-wage ones – so that they can have their own income and stop receiving social security benefits from Centrelink. A group of seniors at a community consultation with service providers in Melbourne told me that receiving financial support for doing nothing is not part of their culture, and they feel guilty being paid for not working.

Resettlement in Australia and other western countries has not been easy for refugees from Bhutan. While the young ones and younger adults face their own problems of adjustment outside their home and intergenerational conflict within the family, life has been one big vacuum for the elderly. The majority of them have never gone to school. They cannot read and write in their first language. They never learned the habit of studying. They didn't have electricity in Bhutan, and had never used basic household utilities like washing machines, vacuum cleaners, gas stoves, microwaves, fridges, or flushing toilets. Everything is new for them.

Seniors’ programs exist in some places of resettlement and run for a few hours per week, but most Bhutanese seniors spend much of their time alone at home while their children and grandchildren go to work and school. As many seniors, particularly men, have experienced severe torture and trauma, they often have complex health issues and many are on some form of medication. Depression and associated illnesses are becoming a big issue for Bhutanese seniors as they are lonely at home on their own, and the future seems like a blur. They fear losing their language, cultural identity and traditional values as their children and grandchildren are influenced by western culture. They are at a disadvantage compared to Australian-born seniors because their lack of English means they cannot advocate for themselves and communicate about issues affecting them without relying on others.

Bhutanese elders would be best served by remaining with their extended families as they grow older. Seniors across Australia have told me they would like to have their own community centre with a Hindu temple to worship, a place to perform their religious rituals, regular programs of bhajan-kirtan, access to Nepali language literature and Nepali language classes for young children. Any aged care support and resources targeted at Bhutanese seniors will be most effective and culturally appropriate if it provides this kind of support and social infrastructure.

For a full list of references, please contact the FECCA office: admin@fecca.org.au
Few of us would dispute that young people are sexual. Recognition of young people’s sexuality has driven policy, education and research. There are comprehensive strategies in Australia to help promote the sexual health of young people; and these encompass lesbian, gay, bisexual, transgender and intersex (LGBTI) youth. But, something changes when we hit 65. It is not that our sexuality suddenly disappears; we still have a need for intimacy and many people continue to be sexually active. Rather, what changes is community perception; there is a widely held belief that people over the age of 65 are asexual.

This article addresses the effects of the myth of asexuality on the lack of recognition of sexual and gender diversity. It also considers the link between perceptions of asexuality and sexual assault. In each case the implications for culturally and linguistically diverse (CALD) communities are considered.

**Sexual and gender diversity**

Older LGBTI Australians have experienced double stigma. Firstly, the belief that older people are asexual has meant that many believe that older people are also not sexually or gender diverse. Secondly, historical experiences of discrimination meant that many older LGBTI people needed to hide their sexuality or gender to be safe earlier in their lives. Historical disclosure of sexuality or gender could have meant imprisonment, shock therapy or the loss of employment, family and friends. For many, the only way to be safe was to hide their sexuality or gender – resulting in a relative invisibility of older LGBTI people in Australia.

The invisibility of older LGBTI people has led many service providers to believe that they do not have any LGBTI clients and that their services do not need to be LGBTI inclusive.

The invisibly of older LGBTI Australians was addressed in 2012 with significant changes to Government policy. In July the *Aged Care Act* was amended to include older LGBTI people as a special needs group. Later that year the Australian Government launched its *National LGBTI Ageing and Aged Care Strategy*, to the applause of LGBTI and human rights groups. These changes recognise, for the first time in Australia, the historical experiences and needs of older LGBTI Australians. The changes spell out for aged care service providers the importance of understanding the needs of older LGBTI clients, and of providing LGBTI inclusive services.

The 2012 changes herald a new era in our history. In this next era, aged care service providers will learn about the historical experiences of older LGBTI people and understand why it is important to create LGBTI inclusive services.

Dr Catherine Barrett

Dr Catherine Barrett is the Manager of the Sexual Health & Ageing Program at the Australian Research Centre in Sex, Health & Society, La Trobe University. The Program includes Val’s Café, promoting the health and wellbeing of older LGBTI Australians and Norma’s Project, which seeks to prevent the sexual assault of older women.
inclusive services involve service providers questioning their own values and beliefs, ensuring cultural safety and valuing (rather than just ‘accepting’) LGBTI clients. In this next era, older LGBTI people will look for signs that it is safe to disclose their sexual orientation or gender identity. They will learn that it is slowly becoming safe.

The next era will also see us acknowledge the diversity within older LGBTI people. Reading Noel Tovey’s amazing book *Little Black Bastard*, we are reminded that his life was not only shaped by his experiences as a gay man, incarcerated at the aged of 17 for being gay, but also as an indigenous man, of the stolen generations. In discussion for this article, Noel reflected on the difficulties experienced by LGBTI people coming out to their diverse cultural community (particularly where being LGBTI is still taboo) as well as the broader community.

In 2009 we established Val’s Café to address and celebrate the complexity of culture amongst older LGBTI Australians. The Café was established to honour Val Eastwood and her infamous 1950s coffee lounge in Melbourne. Val, a lesbian, provided a place of hospitality for LGBTI people at a time when a welcome was hard to come by if your sexuality or gender was labelled ‘different’. Many people of Val’s generation are now receiving aged care services and have the right to the same hospitality and welcome provided by Val. To achieve this, Val’s Café conducts research and advocacy, delivers education and builds community capacity to support those providing services to older LGBTI Australians. Currently, over 200 aged care services have joined Val’s Café. In 2014 we would like to work with CALD communities to address homophobic beliefs and views held by some CALD aged care workers. We would like to document positive strategies for working together at the intersection of cultural and sexual diversity.

*Sexual assault*

Myths about asexuality and older people have also resulted in a failure to prevent the sexual assault of older women. There is a myth that because older women are asexual they are not the targets of sexual assault. However, several years ago, 84-year-old Norma went into respite care and was sexually assaulted by a staff member. Norma’s story inspired a group of researchers to establish a project to prevent the sexual assault of older women. As researchers we were concerned
that the silence about the sexual assault of older women enables assaults continues unchallenged.

The aim of Norma’s Project is to prevent the sexual assault of older women. The project’s primary prevention approach involves gathering evidence about factors that make older women vulnerable to sexual assault. The evidence will then be used to raise awareness as well as inform strategies for prevention.

The ‘gathering evidence’ stage of the Project involves surveys and interviews with older women, family members and service providers. To date over 60 people have shared stories about the sexual assault of women in their own homes, in health services settings and in public places. Perpetrators include domestic partners, service providers and strangers. Participants have told us that older women are not believed when they report sexual assault – because they are older women.

The Project is based at the Australian Research Centre in Sex, Health & Society at La Trobe University and includes researchers from the National Ageing Research Institute and the McCaughey Centre/Centre for Women’s Health, Gender & Society at the University of Melbourne. The project is also being conducted in collaboration with Alzheimer’s Australia and the Council on the Ageing (COTA) Victoria, and was funded by the former Australian Government Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA). The project advisory group includes representation from the Ethnic Communities’ Council of Victoria (ECCV) and we hope to ensure that the Project embraces opportunities to work with CALD communities to prevent the sexual assault of older women.

To date over 60 people have shared stories about the sexual assault of women in their own homes, in health services settings and in public places. Perpetrators include domestic partners, service providers and strangers. Participants have told us that older women are not believed when they report sexual assault – because they are older women.

Conclusions

Our sexuality changes as we age – it does not disappear. There is now increasing recognition that older people are sexual, that they have the right to sexual health and that healthy sexuality can improve wellbeing. As this recognition grows – and funding is available for policy, education and research – it is important to consider the intersection between ageing, sexuality and cultural diversity.

The team from the Sexual Health & Ageing Program at the Australian Research Centre in Sex, Health & Society, La Trobe University are working to address this gap. We are continuing to build partnerships with CALD organisations in Victoria to explore ways of working together to ensure that diversity is recognised and celebrated.

For more information on these projects, please contact Dr Catherine Barrett: c.barrett@latrobe.edu.au or visit www.normasproject.org.au and www.valscafe.org.au.
Supporting Palliative Care for People from Culturally and Linguistically Diverse Backgrounds

Ms Fiona Brooke

Ms Fiona Brooke is National Policy Manager with Palliative Care Australia (PCA). Prior to joining PCA, she spent 23 years with the former Australian Government Department of Health and Ageing. In the 1990s, she undertook the background research and developed pilot programs that later formed the first Ethnic Aged Care Strategy in 1993.

Palliative Care Australia (PCA) advocates for access to high quality palliative care services for all Australians. This role includes ensuring the needs of Australians from culturally and linguistically diverse (CALD) backgrounds are supported and understood by care providers. High quality care meets the person’s needs and upholds their preferences, which are based on many factors including their individual cultural practices and beliefs.

Australia is one of the most culturally diverse countries in the world and will remain that way for generations to come. In Australia, over 300 languages are spoken, more than 100 religions and beliefs are practised and many of the world’s ethnic groups from over 230 different countries are represented. Further, Australia’s ageing CALD population is experiencing more rapid growth than the general population and by 2011 it is estimated that over 1 million Australians aged over 65 will be from CALD backgrounds.

Improving access to high quality palliative care services requires action on many fronts. Palliative care services throughout Australia seek to provide care coinciding with PCA’s Standards for Providing Quality Palliative Care for all Australians. These National Standards were developed by PCA to clearly describe and promote a vision for compassionate and appropriate, including culturally appropriate, end of life care wherever it is provided. Quality, appropriate and comprehensive care is culturally sensitive and requires health professionals to understand each patient’s view of their situation and their expectations of the mode of decision making and type of care that should follow.

PCA recognises that one model of care doesn’t fit all, and we continue to call on all governments to support the development of flexible models of care – in residential, hospital and community settings. This has to be supported by access to qualified translators as needed, together with information in community languages, to ensure patients, their carers and families are able to receive information that is in the best format for them. And supporting this is the need for research to continue to inform ongoing policy and service development.

The concept of patient autonomy and patient-directed care is a key principle in the Australian health context. This approach is not equally applicable across cultural groups and can cause ethical dilemmas for health professionals who associate autonomy with the right to know. In some cases, physician and family based decision-making may be preferred over patient autonomy; family duties and obligations take precedence. Diagnosis may be first conveyed to the family and indirect nuances preferred over truth telling in relation to prognosis. The patient may exercise the right not to know.

Furthermore, tools and treatments considered integral
to the provision of quality care at the end of life are not universally accepted. Advance care directives may be seen as prolonging autonomy when autonomy is not sought. There are also large variations in attitudes towards pain relief. Other cultural considerations may include:

- care settings – there may be strong resistance to institutionalised care;
- language and communication - English language skills are not universal;
- the role of the family in caring;
- diet and food;
- personal care rituals; and
- specific cultural beliefs and religious practices.

People with a life-limiting illness have to know what services are available and how to access them. PCA recognises that this may be a significant challenge for people from CALD backgrounds.

PCA has developed a range of materials in 21 community languages to help provide this information. The brochures provide information about palliative care, managing pain and how to support someone who has been diagnosed with a life limiting illness.

Palliative care services focus on the delivery of care that supports the dignity and physical and spiritual wellbeing of palliative care patients, their carers and their families. Another key focus is on providing care that supports families and carers through the grieving process.

In August, the Victorian Minister for Health, the Hon David Davis, announced a new $400,000 initiative to improve support for dealing with life-limiting illness, death and grief for multicultural communities. The aim of the project is to ensure that people from CALD backgrounds are accessing specialist palliative care appropriate to their needs, at the right time and in their place of choice.

The project is being undertaken by the Ethnic Communities’ Council of Victoria, the Multicultural Centre for Women’s Health and Palliative Care Victoria,

Palliative care services focus on the delivery of care that supports the dignity and physical and spiritual wellbeing of palliative care patients, their carers and their families.
and will use best-practice approaches to raise awareness about palliative care and improve access to these services. During 2013-14, the initiative will focus on the Chinese, Italian, Maltese, Turkish and Vietnamese communities, encompassing a diversity of faiths.

Around 90 peer education sessions about palliative care will be provided by qualified bilingual educators, along with ethnic media and communications. This exciting project will be watched by all palliative care organisations with great interest in order that they can take the lessons learnt and look at how to apply them in their own service delivery.

Specialist palliative care is not generally delivered by a single practitioner. A quality palliative care service may include medical specialists, general practitioners, specialist nurses, allied health practitioners, social workers and pastoral care workers.

These teams are supported by volunteers who provide support and assistance to patients, carers and families in a wide variety of ways. A survey in 2005 reported that up to 60 per cent of the palliative care workforce in Victoria comprises volunteers.

Volunteers are part of the bedrock of palliative care. Many current hospice services began because of volunteers. Indeed, my first experience in volunteering came in the 1980s when I was a volunteer in the group working to establish a hospice in Canberra.

The role of a volunteer in a palliative care service today may be to provide respite or emotional and social support to people when they are at their most vulnerable. Some also assist in supporting organisations, fundraising and promoting palliative care in the community. Other tasks volunteers provide include helping people to go to appointments, working with a person to write an autobiography for their family, taking a patient out for coffee or just sitting with someone and having a chat.

The rewards for volunteers are highly personal. In the same recent Victorian survey, 38 per cent of responders reported that for them, giving back to the community was the best thing about volunteering. Other common responses were satisfaction at using their skills, feeling part of the broader community and feeling needed.

About 30 per cent of those who died in 2011 were born outside Australia, and at least one third of those were from CALD backgrounds. From the Victorian survey, we know that the demographic profile of current palliative care volunteers is ageing and largely Anglo-Saxon. We know that we need to grow our CALD volunteer workforce in order to enable better support for all Australians approaching the end of life.

Palliative Care Victoria has recently developed the first Palliative Care Volunteering Strategy with the support of the Victorian State Government. The new strategy sets out a comprehensive plan for training and supporting volunteers and assisting them to find the right niche in palliative care.


For a full list of references please contact Palliative Care Australia: pcainc@palliativecare.org.au
What Do We Know and What Do We Need to Know?
Compiling the evidence, identifying the gaps and making research accessible to providers of services for CALD older people

Professor Graeme Hugo

Professor Graeme Hugo is ARC Australian Professorial Fellow, Professor of the Discipline of Geography, Environment and Population and Director of the Australian Population and Migration Research Centre (APMRC) at the University of Adelaide. He is the author of over three hundred books, articles in scholarly journals and chapters in books, as well as a large number of conference papers and reports. Professor Graeme Hugo has worked in the field of population research for more than 40 years and has always had a particular interest in older people and ageing populations. He is considered one of the world’s leading demographers and in 2012 he was named an Officer of the Order of Australia (AO) for distinguished service to population research, particularly the study of international migration, population geography and mobility, and through leadership roles with national and international organisations.

This article was co-authored with Dr Helen Feist (Deputy Director, APMRC) and Dr Kelly McDougall (Research Associate, APMRC).

A great deal of attention has been placed on culturally and linguistically diverse (CALD) older populations recently as Australia is confronted with a growing and diversifying older population. The 2011 Australian Census shows that over 1.34 million Australians aged 50+ years are immigrants from CALD backgrounds. This equates to 19.4 per cent, or almost one in five, of all Australians aged 50 years and over.

The issue is important not just within the context of the Australian population as a whole, but is equally important when considering the CALD population specifically. Almost 40 per cent of all immigrants from CALD backgrounds are aged 50+ years, compared to 32.4 per cent of Australia’s total population aged 50+ years, highlighting the more rapid ageing of this section of the Australian population. These population trends are just as significant within the ‘old old’ population too, where 18.5 per cent of the 80+ years population living in Australia are immigrants from CALD backgrounds and 4.6 per cent of all immigrants from CALD backgrounds are aged 80+ years, compared to 3.9 per cent of Australia’s total population aged 80+ years.

These figures are even more confronting if we consider ageing within specific ethnic groups in Australia. For example, 88.4 per cent of all Italian born Australians are now aged 50 years and over and 87.9 per cent of those born in Greece are currently aged 50+ years; Those aged 80 years and over account for over 15 per cent of all Australians born in Latvia, Estonia, Lithuania, Ukraine, Poland, Hungary and Slovenia. For these particular birthplace groups there are more than 1 million people aged 50+ living in Australia who were born in other CALD countries. There are particularly large cohorts currently aged 50+ from Asian and Middle Eastern regions who may have very different expectations and preferences when it comes to ageing well compared to Australia’s current aged population. This reveals the size and diversity we can expect to see in Australia’s older population in the future.
In addition to the increasing population numbers within our communities of CALD older people, there is a recognition that the approaches to best meet the needs of these diverse older populations are limited and often not well understood. A common concern expressed by stakeholders is the dearth of data and research into CALD aged care needs, opportunities and approaches. Those who provide care and support services to older Australians need to be able to access the information and research that allows them to provide better-informed services. It is imperative that services are provided to these older CALD groups with a targeted, evidence-based approach.

Research on issues relating to older people from CALD backgrounds to date has been at best sporadic, leaving opportunities for evidence-based practice and the translation of research into practice problematic.

In order to identify, review and make accessible research and evidence that is available to date, a systematic review of Australian research on older people from CALD backgrounds is being carried out by the Australian Population and Migration Research Centre (APMRC) at the University of Adelaide on behalf of FECCA, funded under the Aged Care Service Improvement & Healthy Ageing Grants Fund, formerly managed by the Australian Government Department of Health & Ageing (DoHA). This review will help to ensure that future programs and research agendas are developed based on a strong evidence base.

A number of strategies will be used to locate the current body of research about older CALD populations, including a comprehensive desktop literature review using a systematic search methodology to identify all published literature related to the following broad areas:

- older people from CALD backgrounds in general;
- older people from CALD backgrounds with dementia;
- ageing CALD people with mental health issues; and
- CALD carers and carers of CALD aged.

The review will also explore other studies that contain data relating to older CALD population groups, but that are not specifically on CALD issues – in particular large national datasets and longitudinal datasets that have the potential to provide further empirical evidence about older CALD population groups.

In addition, aged care, health and other relevant providers or researchers concerned with older CALD populations will be contacted and asked to contribute to the review, and also to identify from their perspectives any research or service delivery priorities for this group and any gaps in the evidence base.

The identified research will be collected, summarised, classified and collated according to the parameters set out by a FECCA reference committee. After the database is completed and reviewed, the results will be disseminated to key stakeholders, policy makers and service providers. The database will be searchable based on key words or criteria so it will be easy for practitioners to select and access the research evidence that is relevant to them. It is anticipated that it will become a valuable tool for the translation of research into practice for all providers of services to older Australians from CALD backgrounds. In addition, this information will be used to inform and guide a new research agenda on issues for older CALD community members in the future.

The goal of the review is to promote better practice, stronger collaborative partnerships and better outcomes for all older people from CALD backgrounds. We appreciate any assistance readers can give us with this project.

Please feel free to contact the project officer working on this project if there is anything you are able to contribute:

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Multicultural Council of the Northern Territory
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About FECCA

FECCA is the national peak body representing Australians from culturally and linguistically diverse (CALD) backgrounds. We provide advocacy, develop policy and promote issues on behalf of our constituency to government and the broader community. FECCA supports multiculturalism, community harmony, social justice and the rejection of all forms of discrimination and racism.

FECCA’s membership comprises state, territory and regional multicultural and ethnic councils. FECCA has an elected executive committee and a professional national secretariat implementing policies and work programs on behalf of its membership and stakeholders.

For more information, you can read about FECCA’s policies and programs at our website www.fecca.org.au.
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