The Congress of Older People's Voices from the Margins Report

The Embolden2023 Collection

celebrate ageing Ltd.

Acknowledgements

We are very grateful to everyone who helped make the 2023 Congress of Older People's Voices from the Margins such a success, including the following people:

Uncle Rick Nelson for his Welcome to beautiful Dja Dja Wurrung Country; Kerrie Tim for a powerful plenary and to all the older people who shared their stories of marginalisation and their strategies for change.

The older people and their representatives who shared their stories and strategies for change, including Gwenda Darling, Dr Katrina Mynard, Steve Grady, Theresa Flavin, Dubhg Taylor, Yumi Lee, Max Primmer, Maddie, David Menadue, Chuping Yu, Yvonne Sillett, Kathy Mansfield, Hayat Doughan, Rachael Brennan, Dr Clare Headland and Shirley Glance OAM.

The service providers who helped facilitate the Design Café, including: Debra Nicholl, Arati Vidyasagar, Sue Petrini, Dominique Horne, Meg Humphrey, Dora Mansbridge, Meg Polacsek, Amber Mills, Paula Ferandez Arias, Ara Creswell, Susie Dunn, Tiarna Jason, Hazel McKenna, Georg Tamm, Rosa Goncalves and Maria Katsabanis.

Artist in Residence Dr Julie Gross McAdam.

Splade to Blade Catering and The Daylesford Good Grub Club.

Our Embolden2023 partners and supporters, including Elder Rights Advocacy, our Principal Partner and the Australian Government Department of Health and Aged Care, Older Person's Advocacy Network (OPAN), Australian Association of Gerontology, ADA Australia, The Older Women's Network NSW, QueerSpace, Drummond St, and COTA Australia.

The team at Celebrate Ageing for their work coordinating the congress, including Dr Catherine Barrett, Tonye Segbedzi, Robyn Smith, Sarah Liversidge, June Lowe, Melissa Williams, Max Primmer and Brian Seaton.

Photography

Thank you to Suzanne Phoenix for the wonderful photographs.

More information

Webpage:
celebrateageing.com/embolden or
celebrateageing.com/margins

Dr Catherine Barrett:
director@celebrateageing.org

Suggested citation

Barrett, C; Segbedzi, T; Smith, R; Liversidge, S; Lowe, J and Williams, M. (2023). The Embolden2023 Collection. Report on the #Embolden2023 Congress of Older People's Voices from the Margins. Celebrate Ageing Ltd, Melbourne.

The Embolden2023 Collection

Thank you

to Djaara Elder, Uncle Rick Nelson, for his warm Welcome to Country.

Thank you also to the Dja Dja Wurrung Clans Aboriginal Corporation.

Contents

Executive Summary

The inaugural ***Congress of Older People's Voices from the Margins*** was held at the **#Embolden2023** Symposium on Ageism and Respect for Older People. An initiative of Celebrate Ageing Ltd, Congress explored how marginalised groups of older people experience ageism – and how ageism marginalises older people.

The process

Presentations by 15 older people (or their representatives) focused on the experiences of Aboriginal people, Auslan users, people living with dementia, people living with HIV, male care partners, people ageing on a farm, dialysis user, LGBTIQ+ people, sex workers, polio survivors, Moslem refugees and older women experiencing homelessness. The presentations related to five categories of marginalisation - gender, ability, place, culture and sexuality.

Following the presentations, a Design Café was led by service providers, policy makers, advocates, researchers, academics and community leaders. The aims of the Design Café were to explore root causes of marginalisation across the presentations and to identify ways to create more inclusive families, communities, services and policy.

Shared themes

Across the presentations by older people, marginalisation was described in similar ways, including the following:

Ignorance:	lack of understanding of unique experiences and needs
Disrespect:	ageist view that older people are homogenous
Grief:	sadness can lead older people to marginalise themselves
Shame:	some older people are ashamed of their disease/ability
Resources:	lack of information and resources for older people
Invisibility:	some older people don't feel empowered to challenge invisibility
Literacy:	lack of technical, cognitive or English language skills to access info
Silencing:	lack of safe spaces to speak and active shutting down
Stigma:	older people who don't comply with social norms are stigmatised
Segregation:	lack of accessible spaces
Contribution:	belief that older people have nothing to contribute.

Root causes

There was general agreement that ageism is a root cause of marginalisation. Other underlying forms of oppression (exacerbated by ageist views of older people as homogenous) contribute to marginalisation and include racism, ableism, sexism, metrocentricity, classism and queerphobia.

Overall recommendations

Insights and recommendations were summarised for each category of marginalisation and suggestions made for how the concept of marginalisation could be utilised (see below). Additionally, the following overall recommendations were made:

Information: review information for older people to ensure it is useful and accessible
Communities: engage local communities to better understand and support marginalised older people
Services: promote inclusive services by identifying the experiences and needs of marginalised older people, removing barriers to service access, educating workers and building inclusive services
Families: identify opportunities to work with families and promote respect for older people
Policies: ensure policies look beyond ethnicity to include the broader cohort of marginalised older people.

Utilising the marginalisation concept

The concept of marginalisation has much to offer approaches to diversity planning and programs to prevent Elder Abuse and other forms of ageism. It views marginalised older people as 'us' rather than 'them' and thereby guides us to an understanding we all play a role in marginalisation and strategies for prevention. Key questions in exploring marginalisation include:

- Which groups of older people are marginalised?
- How are older people marginalised?
- Why are older people marginalised?
- What are the underlying forms of oppression that contribute to marginalisation?
- What strategies can reduce marginalisation and oppression of older people?

Evaluation

An evaluation form was distributed and completed by 37 of the 110 delegates. The evaluation approach drew on the Kirkpatrick Model for feedback on the relevance of Congress and whether participants learned new knowledge or skills that had practical use. A Likert Scale was used (7-point Scale) with the following results:

Relevance:
mean rating 6.51

New knowledge/skills:
mean rating 6.54

Practical use:
mean rating 6.55

When asked if they had plans to utilise what they had learned, 86% said they did and provided examples of their plans.

Keynote & partner messages

Our Time, Kerrie Tim
(Keynote Speaker)

I was born and raised on my Mitakoodi ancestral lands, adjoining the lands of my Kalkadoon ancestors in northwest Queensland. In my early twenties I was told that because I'm Aboriginal I would not live a long life. I decided to plan to live to 120.

There are tough challenges in ageing but there is also joy, intelligence, and courage - needed to continue to grow and to think about what we shall do with the rest of our lives. There are big problems - climate emergency, pandemics, racial injustice, violent conflict, and economic inequality - that require immediate, creative solutions. We Elders have the experience and perspective to join with others to become a powerful force in restoring the health of our planet and lead people to a rational, peaceful society.

Indigenous Elders inherit responsibilities that come with moral obligations. Indigenous leadership is life-long: it's based on life-long learning; it is relationship-based; it considers positions of leadership as well as the responsibilities that come with the practice of leadership; and it places on us an obligation founded in responsibility for those who come behind, for all life, and for country.

We connect with you and other Elders in a special bond: Elders are as precious and essential to human society as all other humans. Society would be lost without our contribution, without us!

Dr Catherine Barrett, Director of Celebrate Ageing Ltd

The *Congress of Older People's Voices from the Margins* is an initiative of Celebrate Ageing Ltd, a charity combatting ageism and building respect for older people for over a decade. Celebrate Ageing bridges the evidence-to-culture gap through art and narrative based approaches that help to engage the critical mass required for culture change.

Equity for marginalised older people is a priority for Celebrate Ageing. Our work with marginalised older people includes projects, programs and Fellowships with the Elder Leadership Academy. The addition of Congress to Embolden provides an opportunity to explore the relationship between marginalisation, ageism and respect for older people. We are incredibly grateful to the older people who share their stories and the service providers and community leaders who participated in the Design Café to help us reimagine a more equitable world.

Congress is now firmly fixed in our annual Embolden Festival – and we look forward to exploring how we can expand our understandings and use this knowledge as a catalyst for action to promote inclusion and equity.

Thankyou to everyone who supported Congress and we hope you will also read The Embolden Collection report on the Embolden Festival.

Debra Nicholl, CEO Elder Rights Advocacy - Principal Partner

Elder Rights Advocacy is proud to have been the Principal Partner for the #Embolden2023 *Congress of Older People's Voices from the Margins*. At Elder Rights Advocacy we support older people to access aged care services, know their rights and resolve problems with aged care service providers.

We are committed to empowering and supporting older Victorians to stay in control, stay connected, make informed decisions and plan ahead. We know that many older people who are marginalised face significant barriers to achieving these goals. We want to understand more about the barriers, so we can help to overcome them.

Thank you to the older people who shared experiences of marginalisation and their suggestions for a more inclusive world. You have the right to respect and support and we are working to help you achieve that. Please reach out to our team if we can assist you in anyway.

Elder Rights Advocacy is a member of the Older Person's Advocacy Network or OPAN. In Victoria, phone 1800 700 600 or (03) 9602 3066 Monday to Friday, 9-5 pm. We can arrange an interpreter or translator. In other states/territories, phone OPAN on 1800 700 600 between 8 am and 8 pm Monday to Friday to be put through to your local advocate. More info: elderrights.org.au

Introduction

This report summarises the inaugural Congress of Older People's Voices from the Margins, held at the **#Embolden2023** symposium.

Embolden is Australia's only national event focused on combatting ageism and building respect for older people. Established in 2018, the aim is to embolden – or build capacity and confidence - of service providers, policy makers, community leaders, older people and everyone who works with or for older people, to accelerate the pace of change.

The **#Embolden2023** event included a Symposium (see overall report celebrateageing.com/embolden) and Congress. The aim of Congress was to explore how marginalised groups of older people experienced ageism and respect – to inform more inclusive and compassionate responses to older people.

Congress included presentations by older people and a Design Café led by service providers to explore more inclusive families, communities, services, communities and policy.

Marginalisation, ageism and respect

There is growing recognition of the ageism experienced by older Australians and the subsequent problems of Elder Abuse, family violence, workplace discrimination and the diminished confidence, health and wellbeing of older people.

Ageism marginalises older people – directly through disrespect, silencing, invisiblizing, devaluing, shaming, segregation, violence and abuse – and many other ways. Ageism also marginalises older people indirectly by assuming they are a homogenous cohort and failing to combat other forms of oppression older people face. These direct and indirect factors were explored at Congress and are the focus of this report.

About this report

The purpose of this report is to share the presentations by older people and the key insights and recommendations from the Design Café. It is a legacy document to help build momentum for change. Key sections include:

- A summary of Congress processes
- Key insights and recommendations
- An evaluation summary
- Extract of papers presented by older people.

It begins with messages from our Principal Partner, Elder Rights Advocacy and an extract from the keynote address by Kerrie Timms.

About Congress

The inaugural Congress of Older People's Voices from the Margins was held at #Embolden2023; an annual event promoting the capacity of individuals, groups and services to combat ageism and build respect for older people. Congress provided an opportunity to explore how a focus on marginalisation could help to create more compassionate and inclusive responses to older people.

The overall Embolden program was underpinned by a critical theory approach. Applying a critical theory lens to development of the program – and particularly Congress, guided critique of current values, beliefs, attitudes and behaviours towards older people. The program drew on theory by Habermas[1] that critique is necessary for changing practice – or culture.

The critical theory approach also guided production of outputs, or resources (such as this report) to guide action taken by delegates after the event. It is important that delegates left the event inspired and with resources for change.

The resources were shaped by critical theorems[2], or small theories about how the world is (power) and what must change. A critical theorem was developed for each subtheme, including marginalisation and posted on the walls of the Town Hall, alongside a call to action. Delegates were invited to provide feedback on these as the event progressed.

1 Geuss, Raymond (1981). *The Idea of a Critical Theory*. Cambridge University Press

2 Grundy, S. (1982). Three modes of action research. *Curriculum Perspectives 2*(3): 23-34.

Marginalisation

While the concept of marginalisation is less commonly utilised than diversity – it offers something quite unique. Not every older person from a diverse group is marginalised and not every marginalised older person is from a diverse group.

Marginalisation simply put is about being treated as less important. People who are marginalised experience stigma and discrimination. They are often not treated as equal and have less power and capacity to assert their right to full citizenship.

Marginalisation involves treating a person or group of people as insignificant, relegating them to an unimportant or less powerful position, or excluding them from the dominant culture.

Ageism marginalises older people – and older people may also be marginalised based on their gender, ability, place, culture, sexuality, or other characteristics. This is often referred to as intersectionality and an older person may have multiple characteristics that lead to marginalisation.

Some diverse groups of older people are marginalised, and others are not. Applying a marginalisation lens raises useful questions about what inequalities exist and how they can be reduced. There is an implicit understanding that an older person who is marginalised has been 'pushed away' from the mainstream, and that this is something that can be rectified.

The concept of marginalisation is relatively easy to grasp – a critical factor in creating momentum for equality. Most people have experienced marginalisation (even from a brief period) and understand the adverse impacts. The relatability of the concept of marginalisation provides a useful point for understanding how protracted or persistent marginalisation can adversely impact an older person's health and wellbeing.

Taking a marginalisation lens to combatting ageism or prevention Elder Abuse does not negate the value of diversity frameworks; rather it encourages deeper reflection on the key issues, highlights power imbalances and strategies for change.

Marginalisation positions power imbalances as being about 'us' rather than 'them' – or - something that happens in diverse communities. It suggests we are all part of the problem and the solution.

Marginalisation positions power imbalances as being about 'us' rather than 'them'.

Aims of the Congress

Congress sought to explore how marginalised groups of older people experience ageism – and how ageism marginalises older people. The specific aims were to:

- Provide a space to hear about the experiences and needs of groups of marginalised older people – how they experience ageism and their strategies for change
- Work with delegates to reflect on the causes of marginalisation and our role in reducing marginalisation
- To identify strategies to develop more inclusive families, services, communities and policies.

Congress was structured around presentations by older people and a Design Café, as outlined below.

Listening to older people's voices

Prior to #Embolden2023 a call out was made via networks, email and social media for older people from marginalised groups to share their experiences at Congress. Fifteen older people (or their representatives) responded to the following questions:

- Can you tell us about the overall experiences of the group of older people you are representing?
- What factors contribute to marginalisation of older people in this group?
- In relation to ageism and respect for the older people you are representing – what is going well and what needs to be improved?
- What is one thing people can do right now to help reduce marginalisation for the group of older people you are representing?

Participants were invited to share a brief presentation at Congress and to write up a paper for this report and the webpage. Most participants worked with Congress Coordinators to write up their paper and clarified that their perspective may not reflect the voices of all older people in their marginalised group.

Presentations included Aboriginal people, Auslan users, people living with dementia, people living with HIV, a male care partner, people ageing in rural communities, a dialysis user/donor recipient, LGBTIQ+ people, a sex worker, a polio survivor, a Moslem woman and an older woman who has experienced homelessness.

While there are likely hundreds of marginalised groups of older people, and only 15 represented at Congress – the breadth of presentations was remarkable. Excerpts from the papers are attached to final section of this report and available in full on the Margins webpage (celebrateageing.com/margins).

Following the presentations by older people, a Design Café was hosted to explore the issues and identify recommendations.

Design Cafe

Following presentations by older people, Congress delegates were invited to participate in a Design Café. The Café involved service providers, policy makers, advocates, researchers, academics and community leaders leading discussion on the papers and how to redesign services, communities, policies and families to be more inclusive of older people who are marginalised.

The Design Café included 16 service providers from aged care advocacy and assessment, community care, dementia services, policy, professional associations, Queer organisations and academia.

The Design Café Team were given copies of the papers by older people prior to Congress, as well as an outline of their roles. An online meeting was also facilitated for the Design Team to meet and clarify Congress processes.

The papers written by older people were categorized into key themes prior to Congress, revealing the following five categories of marginalisation: gender, ability, place, culture and sexuality. It was noted that most papers related to multiple categories of marginalisation.

Five tables were established, one for discussion on each category, and delegates were invited to visit each table to share their suggestions for designing more inclusive families, communities, services and policies. The design team were invited to guide conversation and document key responses.

A sixth table was established to explore the root causes of marginalisation and overall strategies to prevent marginalisation.

It is important to note that the five categories do not represent all the ways in which older people are marginalised. A different set of papers would result in new categories – and these will assist in expanding the understanding of marginalisation in years to come.

Great presentations and demonstrated a great insight into the various worlds of the Australian ageing community.

Key insights and recommendations

The following section outlines feedback from the Design Café, beginning with reflections on the root causes of marginalisation and strategies for prevention. Then key insights and recommendations for change related to the five categories of marginalisation are presented.

Marginalisation

The first activity for the Design Teams was to identify shared themes across the experiences of the older people who presented. The following themes were identified:

1. **Ignorance:** older people may be unseen or unheard where there is a lack of understanding of their unique experiences and needs by their families, community members or service providers. This ignorance may not be motivated by ill intent, but nevertheless it contributes to marginalisation
2. **Disrespect:** ageism contributes to a view that older people are a homogenous group e.g.: one age (despite 'old' referring to four or more decades), genderless, sexless and cultureless
3. **Grief:** an older person may marginalise themselves because they feel sadness or grief about where their life is at
4. **Shame:** older people may feel shame related to their disease (e.g.: HIV or dementia) or other characteristic and isolate themselves
5. **Inadequate resources:** the lack of information and resources to support older people can lead to marginalisation e.g.: inadequate support for care partners or lack of resources to support later life transition
6. **Invisibility:** some older people are marginalised because they are invisible and don't have time or agency to advocate for their needs e.g.: carers and sex workers
7. **Literacy:** some older people do not have technical, cognitive or English language skills to access information about their rights and services that could support them
8. **Silencing:** some older people's voices may not be heard because safe spaces are not provided for them to speak. Others may be intentionally silenced by those who fear disruption or believe the older person is a threat to existing power dynamics. These responses may have their origins in racism, sexism, ableism and queerphobia. Others may be silenced by lack of access to translation and interpreting services, including Auslan interpreters
9. **Stigma:** some people marginalise older people, such as older sex workers or LGBTIQ+ people because they don't comply with social norms
10. **Segregation:** some groups of older people are marginalised by lack of access to accessible spaces
11. **Contributions:** some older people are marginalised by the ageist stereotype that they have nothing to contribute because they are an older person.

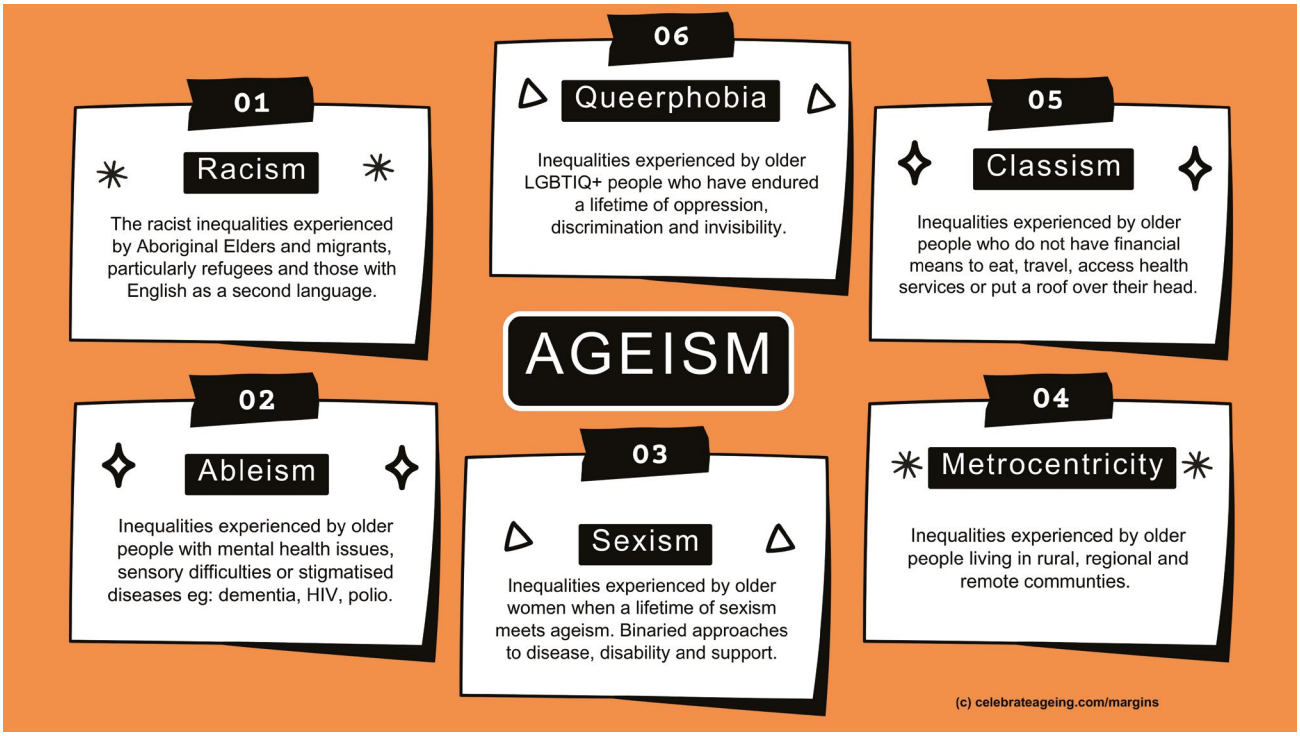

Figure 1: Root causes of marginalisation and underlying forms of oppression

Root causes and oppression

Congress delegates were invited to discuss the root causes of the marginalisation described in the presentations. Ageism was identified as the primary root cause with six underlying forms of oppression also identified – as shown in Figure 1 and described above.

As the Figure above shows, ageism was a central root cause underpinning marginalisation in all the presentations. The mechanism of ageism worked in two ways. Firstly, older people were valued less and treated with disrespect because of their age. Secondly, ageist views of older people as a homogenous cohort resulted in the diversity of older people's lives and experiences not being seeing or valued and consequently older people are further marginalised.

The root causes outlined reflect the papers presented at Congress – and the feedback provided. A different set of papers and delegates may have identified a quite different set of root causes. However, the point of the Design Café was not to reach consensus or agree to any one truth – rather it was to explore how older people are marginalised and the role we all play in reducing marginalisation. As one delegate wrote:

I think it is important to talk about "marginalisation" not diversity or vulnerability because it positions the issue in the right place … i.e.: ***I don't need to be 'fixed' but I need to fix how I am treated, seen, not seen, stereotyped, excluded.*** It means we turn to media, education etc to address the issues – power structures, systems of exclusion, not further 'othering'.

However, rather than discard concepts of diversity – an exploration of marginalisation may offer a way for us to better understand diversity and how to be inclusive - by asking the following questions:

- Which groups of older people are marginalised?
- How are older people marginalised?
- Why are older people marginalised?
- What are the underlying forms of oppression that contribute to marginalisation?
- What strategies can reduce marginalisation and oppression of older people?

These questions may assist us to understand diversity beyond the limited view of ethnicity. The questions can guide us to an understanding that we all have a role to play to reducing the marginalisation and oppression experienced by older people.

Recommendations

The Design Teams engaged delegates in discussion about strategies to combat these root causes of marginalisation. Recommendations included:

- *Valuing older people*
- *Respect, equity, inclusivity for older people*
- *Promoting representation and visibility of older people*
- *Addressing discrimination – particularly ageism*
- *Positive role models - Celebrate Ageing!!!!!!!*
- *Connected communities*
- *Building intergenerational relationships*
- *Education – introducing young children to older people – understand how to interact and just be nice!!*

In addition to the exploration of these root causes, delegates were also invited to work with the Design Team to explore **five categories of marginalisation** i.e.: gender, ability, place, sexuality and culture. Feedback from the design teams is summarised on the following pages.

Gender

Gender was defined as the socially constructed characteristics of men, women and Trans and Gender Diverse (TGD) people; and including norms, behaviours, roles, relationships and inequalities.

Insights

Presentations focused on male perspectives on renal dialysis, being a care partner and living with dementia

1. It was noted that some older men feel emasculated by their experience of disease, disability or being a care partner – and there are related self-harm and mental health issues
2. There was general agreement about a failure to support older men to rethink 'traditional' male roles in preparation for ageing and significant life changes
3. One presentation explored gender inequalities for older women and referred to research showing older women are: the lowest income earning family group (see here), the largest group of unpaid carers - 70% of carers are women (see here), the fastest growing group of homeless - increase of 31% between 2011-2016 (see here), more likely to live in poverty - 34% of single older women live in poverty (see here) and more likely to experience workplace discrimination (see here), Elder Abuse (see here) and more likely to be sexually assaulted (see here)
4. It was noted that The Status of Women Report Card, 2023 shows that Australia is ranked 43rd in the World for Gender Equality – indicating there is significant room for improvement
5. Ageist misconceptions of older people as genderless can result in a failure to take a 'gender lens' to services and strategies for older people
6. Two papers related to the experiences of Trans and Gender Diverse older people, including family violence, elder abuse, violence and transphobia from the broader community, Transphobia within Queer communities and limited opportunities historically to explore authentic self-including transition
7. Growing numbers of TGD people are transitioning in their old age and face unique experiences of Elder Abuse including rejection by family where there are well established gender roles and expectations, and limited possibilities for physical transition.

Recommendations

1. Education is needed for policy makers and service providers on what gender is, what gender equality means for older people and how gender influences experiences of and responses to disease and disability
2. Policy makers and service providers need to take a 'gender lens' to planning and improvements
3. Education is required for policy makers and service providers on the experiences and needs of older TGD people
4. Services should be TGD inclusive and this includes policy, education and strategies to send a message of welcome e.g.: including pronouns on email signatures etc
5. Promoting gender equality in services is not the responsibility of individual older people – the responsibility rests with services.

Ability

Ability refers to physical and mental capabilities and includes physical disability, mental health issues and disease.

Insights

1. Papers explored the stigma and discrimination of some diseases e.g.: dementia, HIV and polio and the consequent marginalisation
2. Often it is not the disability or disease that results in marginalisation – it is
   a) the stigma or discrimination generated by others
   b) shame felt by the older person with disability/ disease
   c) lack of information and education
   d) the limited conversations about the stigma and discrimination
3. Mental health issues are experienced by many older people who are marginalised
4. Examples of ageism include the experiences of people living with dementia with what Kate Swaffer refers to as 'prescribed disengagement'
5. People living with dementia are perceived as less than human – and are more than twice as likely to not see friends - compared to general public
6. Polio survivors were expected to be invisible – were told they would not have a disability unless they were 'lazy'
7. People living with HIV were and still are stigmatised – the greatest predictor of subjective wellbeing for HIV positive older gay men is stigma and discrimination in services
8. Older Deaf people who need an Auslan interpreter to communicate effectively may find themselves isolated by the lack of understanding of the need for interpreters.

Recommendations

- Policies need to address accessibility for older people of all abilities and should be codesigned with older people who are marginalised on the basis of their ability
- Education is needed to support carers to meet the needs of the people they're caring for e.g.: continence management – normalise it
- Ensure people with lived experience are represented behind the scenes and out in front as well - use co-design at every step.
- Promote media inclusivity
- Normalise conversations about ability
- Make Auslan translation/interpretation normal practice
- Simplify service language and remove professional jargon and acronyms from information for older people
- Promote older role models with disability
- Promote access to services by adequately explaining services available
- Offer older people support to name their issues, talk about and through them.

I thought I was really conversant with marginalisation in aged care but I came away thinking about the many faces of marginalisation.

Place

Place refers to where we live and is also a psychological concept, encompassing a sense of belonging that arises from being seen, heard, valued and supported.

Insights

1. Place is geographical concept, referencing where we live – e.g.: metro, rural, remote. It can also be a psychological concept, referring to a sense of belonging, connection and community. Where our roots are. In Gaelic, place means where your heart and soul are
2. Older people may be [dis]placed by homelessness or by the experience of family violence/elder abuse in their own home
3. Ageism displaces older people – and to be [dis]placed is to be marginalised
4. A sense of place is important to all of us – its significance doesn't diminish as we age. Place is about belonging and a sense of identity, connection, attachment, geographical location, value, purpose and identity. Place is being seen, being valued and being supported
5. Older people from marginalised groups may be displaced by the dominant culture. Aboriginal Elders have been displaced by white 'settlement'. Migrants and refugees may be particularly at risk of culture shock and displacement
6. A paper on male carer partners highlighted how invisibility and lack of support can displace an older person who is a care partner
7. A paper on older sex workers emphasised how stigma and discrimination can displace older people
8. Some LGBTIQ+ veterans were 'dis-placed' by the armed forces when their LGBTIQ+ness was disclosed
9. A paper describing ageing on a farm illustrated how older people in rural and remote communities may have less access to support and experience loneliness – but may live in communities where they are valued
10. Two papers described older women's experiences of being homeless, beyond sleeping rough/on the street – including couch surfing and living in a caravan.

Recommendations

- Research is needed to better understand what place means to older people, the importance of place, what displaces older people and how a sense of place can be promoted
- Education is needed for service providers and policy makers on the role place in the lives of older people
- Services and policies need to take into account strategies to promote a sense of place
- Strategies to combat ageism should consider the role place plays in older people's health and wellbeing; and how attitudes (particularly ageism) can displace an older person.

Sexuality

Sexuality includes an older person's identity, attraction and sexual behaviours towards other people.

Insights

1. Sexuality is more than who a person has sex with – it encompasses self-identity, culture and behaviour
2. There is a commonly held ageist myth that older people are asexual
3. The myth of asexuality results in older people's sexual rights not being promoted
4. The myth that old age is a protective factor against sexual assault is fed by ageist perceptions of asexuality (and the myth that sexual assault is motivated by sexual attraction)
5. Sexual assault of older people and people living with dementia is a problem in residential aged and at home
6. Older people and people living with dementia have limited access to education and resources on negotiating sexual consent
7. Most service providers have not been educated on promoting older people's healthy sexual expression
8. It was noted that the past decade has seen recognition of older LGBTIQ+ Australians and in 2023 the UN published a paper on Human Rights of Older LGBT People
9. Some older gay men, lesbians, bisexual and pansexual people have lived most of their lives knowing that they were considered 'bad' and could be incarcerated because of their sexuality. And that they could be forced to undergo so called 'cure' treatments including electric shock
10. For some older LGBTIQ+ people, being their authentic selves can mean rejection by other communities e.g.: defence force, church, older people's social groups
11. Older people who come out late may experience Elder Abuse or Family Violence by Queerphobic families (including restrictions to sexual expression)
12. Some older LGBTIQ+ people have never known a time it was safe to be who they are, and although they have more rights now, some continue to feel oppressed.

Recommendations

- Older people need access to education and resources on their sexual rights, including their right to be free from sexual assault
- Older people have the right to access information on affirmative approaches to sexual consent
- Policies are required to guide aged care service providers in promoting older people's sexual rights
- Aged care service providers need access to education on older people's sexual safety and wellbeing
- Service providers need to understand that older people's sexual identity and behaviour may vary depending on their culture
- Service providers and family members need to understand older people's sexual choices and expression may change over time and in response to disease or other life changes
- Service providers need to acknowledge older people's sexuality as a right – not a problem
- Remove legal restraints for older people to access sex workers
- Education is needed on the unique experiences and needs of older LGBTIQ+ people and implement strategies to promote LGBTIQ+ inclusive services.

Culture

Culture in this context refers to a group of people who share a core set of beliefs, patterns of behaviour and values. It includes ethnicity but is a broader concept.

Insights

1. Presenter Kerrie Tim highlighted Aboriginal Elders are "*strong, energetic, and intelligent*" people who have made significant contributions and "*amassed a tremendous amount of much-needed knowledge, experience, and perspective*." These skills were necessary to come up with immediate and creative solutions to "*racial injustice, violent conflict, and economic inequality*". Kerrie added that Aboriginal Elders have "*the experience and perspective to join with others to become a powerful force in restoring the health of our planet and lead people to a rational, peaceful society*."

2. It was noted Amnesty International's Facts on Racism show that in Australia, Aboriginal people experience the most racism, contributing to shorter life expectancy (by 10 years) and death rate 5 times the rate of non-indigenous people. Their research also shows that while 84% of Australians believe in freedom from discrimination – only 47% Australians believe there is a problem with racism

3. It was noted that Amnesty International Research shows 80% of Muslim Australians experienced unfavourable treatment including hate, violence or negative comments in public

4. Culturally diverse older Australians may have experienced a lifetime of trauma related to war, immigration and discrimination

5. The Design Table for Culture focused primarily on the concept of ethnicity – as other some other forms of diversity (e.g.: older LGBTIQ+ people) were covered on other Design Tables. However, it was noted that too often approaches to diversity are limited to ethnicity – rather than understanding marginalised older people more broadly.

Recommendations

- Policies and services need to promote an intersectional lens to assessment, care planning and service provision
- Policies and services need to promote equity (resources/opportunities are allocated to ensure all older people have equal access and outcomes) – rather than equality (every group is given the same resources/opportunities)
- Marginalised older Australians need to be included in all facets of service planning and evaluation
- Policies and services need to identify systemic barriers experienced by older people who are marginalised and utilise this information improve access to services
- Codesigning policies and services with marginalised groups of older people is a critical step towards equity
- Providing support to marginalised communities to support their older people may be an effective strategy in reducing marginalisation
- Services who state their commitment to understanding and eradicating marginalisation are more likely to build trust and promote equity
- Place based solutions are particularly important for older people who are marginalised.

Loved the diversity of life experiences... this is real life.

Overall recommendations

The concept of marginalisation requires a shift from equality (every older person is allocated the same resources/opportunities) to equity (resources/opportunities are allocated based on the individual's circumstances and needs, to ensure all older people have equal access and outcomes). Overall recommendations for reducing the marginalisation of older people include:

1. **Utilise the concept of marginalisation**
    a. Ask the following key questions
        - Which groups of older people are marginalised?
        - How are older people marginalised?
        - Why are older people marginalised?
        - What are the underlying forms of oppression that contribute to marginalisation?
        - What strategies can reduce marginalisation and oppression of older people?
    b. Understand the harmful impacts of marginalisation on older people
    c. Understand that we all have a role to play in reducing the marginalisation of older people
    d. Understand that ageism is a major root cause of the marginalisation of older people.

2. **Review access to information**
    a. Ask marginalised older people what information they need
    b. Provide older people with access to the information they need
    c. Engage local communities
    d. Work with marginalised older people to identify the community supports they need
    e. Promote education in local communities to build an understanding of the experiences and needs of marginalised older people
    f. Engage local communities in supporting marginalised older people
    g. Promote opportunities for multigenerational collaborations.

3. **Promote inclusive services**
    a. Service policies need to identify older people who are marginalised and shape services in response to their needs
    b. Barriers to service access need to be reduced or removed
    c. Worker education should include the concept of marginalisation and the role we all play in reducing it.

4. **Work with families**
    a. Identify ways to work with families to help them understand and value their older people
    b. Families are a source of marginalisation – but also often greatly valued by the older person
    c. Model respect for older people in families.

5. **Co-design policies**
    a. Policies relevant to older people need to consider the concept of marginalisation – to ensure that older people are included
    b. Approaches to diversity should look beyond ethnicity to consider the broader cohort of older people who are marginalised.

In addition to the overall recommendations outlined above – the following Critical Theorem and Call to Action was developed

Marginalisation

Critical Theorem & Call to Action

Critical theorem: The concept of marginalisation has much to offer approaches to diversity planning and programs to prevent Elder Abuse and other forms of ageism. It views marginalised older people as 'us' rather than 'them' and guides us to an understanding that we all play a role in marginalisation and strategies for prevention.

*We the delegates at #Embolden2023 invite consideration of **Marginalisation** and older people, as summarised above and outlined below.*

The word Marginalisation was used at #Embolden2023 to refer to treating an older person or group of older people as less significant, relegating them to an unimportant or less powerful position in society, or excluding them from dominant culture. Older people who are marginalised are not treated as equal.

Ageism marginalises older people, and older people may also be marginalised on their basis of their gender, physical or mental ability, place, culture, or sexuality. This is often referred to as intersectionality, and an older person may have multiple characteristics that lead to marginalisation.

Some diverse groups of older people are marginalised, while others are not. Applying a marginalisation lens raises useful questions:

- Which groups of older people are marginalised?
- How are older people marginalised?
- Why are older people marginalised?
- What are the underlying forms of oppression that contribute to marginalisation?
- What strategies can reduce marginalisation and oppression of older people?

The concept of marginalisation has much to offer approaches to diversity planning and programs to prevent Elder Abuse and other forms of ageism. It views marginalised older people as 'us' rather than 'them' and guides us to an understanding that we all play a role in marginalisation and strategies for prevention.

The concept of marginalisation is relatively easy to grasp, a critical factor in creating momentum for equity. Most people have experienced marginalisation (even for a brief period) and understand the adverse impacts. The relatability of the concept promotes understanding that protracted or persistent marginalisation can devastate an older person's health and wellbeing.

Marginalisation is an important lens to consider in: developing information for older people, engaging local communities, promoting inclusive services, working with families and ensuring inclusive policies.

Congress evaluation

An evaluation form was distributed at the end of Congress and was completed by 37 delegates. The aims of the evaluation were to check Congress was useful to delegates and to identify opportunities for improvement.

The evaluation approach drew on the Kirkpatrick Model, reviewing four levels of the education (Congress) i.e.: participants reaction, learning of new knowledge and skills, and plans for behaviour change.

To explore these levels, participants were given statements about the relevance of Congress, whether they learned new knowledge or skills and whether the knowledge/skills had practical use. Participants were asked to record their level of agreement with the statement using a 7-point Likert scale (strongly disagree, disagree, somewhat disagree, neither agree nor disagree, somewhat agree, agree, strongly agree) with higher score indicative of higher agreement.

A fifth level in the Kirkpatrick Model relates to outcomes and documenting the degree to which education participants have made change. To explore this level, a brief online survey will be circulated to delegates in April 2024.

A final question asked participants whether they had plans to make changes in response to what they had learned (yes/no). Overall the ratings were high on all levels (see following pages) and comments indicate Congress was very well received. Overall comments include the following:

- *The session was informative and necessary*
- *Great presentations and demonstrated a great insight into the various worlds of the Australian aging community*
- *Well run: well facilitated: intelligent - substance and way it's run*
- *A simple thank you for bringing us together*
- *What a fantastic event. Loved the stories, welcome country, variety of marginalised people speaking, networking opportunities and June's activity [on marginalisation] - clever! Unfolded well - (smiley face) well done!*
- *It was fabulous. I really really appreciate the inclusiveness of the attendees - in reality, not just in words - involving Mum supportively and respectfully and hearing what I had to say*
- *Well organised - thank you to Catherine and all those from Celebrate Ageing. Meeting new people from other organisations was very important*
- *Very inspiring event. I am keen to make some changes based on what I've learnt. Wonderful speakers with great stories to tell, it's a shame we didn't have time to hear more*
- *Such important education and learning for me, hearing directly from people is so powerful*
- *Congratulations to Catherine and the Celebrate Ageing members for an amazing congress. Well done!*
- *Absolutely brilliant day!*
- *I was most impressed with the whole project.*
- *Bravo! Amazing!*
- *Thank you for creating this amazing space for learning and sharing. Thank, thank you, thank you (big smiley face).*

Over the following pages, the ratings and comments for each of the questions is presented.

Relevance

Most delegates (62%) strongly agreed with the statement that Congress was relevant to them, others agreed (27%) or somewhat agreed (11%) with a mean rating of 6.51 out of 7. Participant comments about relevance included:

- *Loved the diversity of life experiences.. this is real life*
- *Hats off to the organisers for curating such a line-up. It was very powerful to hear these voices - especially in succession*
- *It was brilliant to hear all the different stories and voices. Of course, relevant to reflect on and learn from these different lived experiences*
- *It allowed many different stories to be told and it was beautiful to see the diversity of ageing*
- *The stories shared showed how marginalised our ageing population is and how this is multiplied when other factors are added; gender, illness….*

New knowledge and skills

Most delegates (65%) strongly agreed with the statement that they had learned new knowledge or skills at Congress, others agreed (24%%) or somewhat agreed (11%) with an average rating of 6.54 out of 7. Participant responses to the invitation to comment about new knowledge and skills included:

- *Discovered issues that I have not considered before*
- *Great hearing from people affected by issue; respectful engagement; lots of 'new' information*
- *I thought I was really conversant with marginalisation in aged care but I came away thinking about the many faces of marginalisation*
- *Absolutely!*
- *The insights shared by people living with dementia were profound, as was the challenges from older women, sex workers and trans woman*
- *I learnt how it feels to be a person with that lived experience e.g.: living with dementia, polio, being a Muslim migrant in Australia*
- *Learning about the many issues among the diverse voices inc trans gender, ageing in rural areas*
- *Taking time to network with other organisations. Taking time to listen to the stories that our elders have to share, advocating for them, being with them.*

Practical use

Most delegates (59%) strongly agreed with the statement that they will be able to use the new knowledge and skills gained at Congress, others agreed (23%) or somewhat agreed (18%) with an average rating of 6.55 out of 7. Participant responses to the invitation to share how they might be able to use the new knowledge/skills they gained at Congress included:

- *Greater awareness of disability/diversity*
- *Will pass on to Policy at DOHAC*
- *Sharing with colleagues and policy areas at DoHAC*
- *With other elders' groups, in leadership work, with family and friends*
- *Always remember to include the diversity of humans*
- *Include people's stories to make an impact; be more mindful of being inclusive of diverse older Victorians and their needs and reflecting this in our work and decisions and consultations*
- *I think more than knowledge/skills it is connections!*
- *You've offered me breadth and an invitation to widen my understanding of experiences outside my own*
- *I will be able to share my knowledge gained to explore opportunities for healthy ageing*
- *With the volunteer work I do, and be able to pass more knowledge on*
- *Opening conversations with my organisation and with my clients*
- *Simplifying process for those accessing out services, using less jargon/ abbreviation.*

Plans for change

Most delegates (86%) said they plan to change something in response to what they learned at Congress. When asked to provide comment on what they would change, participants wrote:

- *Will enhance critical reflection, thanks!*
- *Learn more, implement in my life and other efforts. I'll be able to tell you this next year!*
- *Inspired to find such openness in services and government and policy makers and encourages me to reach out and connect more*
- *Share my knowledge with people on my team, friends and family. I will pass this knowledge onto friends and work colleagues.*
- *I will take learnings to encourage changes at my workplace e.g.: ensuring that marginalised groups are considered when developing resources*
- *I will change my way of thinking and hopefully talking about being old*
- *Think about 'marginalised' and have that inform my actions*
- *Perception on marginalisation*
- *I hope my awareness will remain widened*
- *I think I will be more open to listening to, and helping to 'platform', such diverse voices and perspectives*
- *To try to be as inclusive as possible*
- *More awareness of disability/diversity*
- *Will discuss some of the issues discussed with smaller organisations and providers*
- *I will change a lot of my chats with people and be more open.*
- *Keep those discussions at the forefront of everything we do*
- *Try to integrate the learning into programs we run*
- *Make sure I get the full story of what people are going through.*

Improvements

Suggestions for improvements were highlighted by several participants and will be considered in the planning for Congress for 2024. In summary, suggested improvements included:

- *More scheduled breaks*
- *More time for older people to present*
- *More time for discussion*
- *Q and A following older people's presentations*
- *Icebreaker activity*
- *Consider options for design café to promote discussion and debate*
- *Consider implications for delegates to utilise storytelling in their workplaces and communities.*

Inspired to find such openness in services and government and policy makers and encourages me to reach out and connect more.

Extracts from the Papers

The following section presents extracts from the 15 presentations by older people (and their representatives). The full papers are available at: celebrateageing.com/margins.

Aboriginal people living with dementia, Gwenda Darling

Dementia was a listed in the DSM as a mental illness and people living with dementia were considered mad and somehow infectious. That was the start of stigmatisation of dementia. Some people still believe dementia is mental illness or that mental health issues cause dementia.

In some Aboriginal communities it is more acceptable to have mental health issues than it is a dementia diagnosis. Dementia has a lot of stigma. For some people it can be more acceptable for them to believe dementia is a mental illness and that they are mad – because madness is curable. It's easier to say they have mental health issues than it is to say they have dementia.

If someone in your family has dementia – take a strengths-based approach. Focus on what we can do. Don't feel sorry for us. Be encouraging. And if we do something that you wouldn't do or something we might not have done in the past – don't take that on as a reflection on you. Don't be ashamed – it doesn't help.

We need to take away the misinformation and fear. Dementia isn't contagious and we are not going to hurt you. Don't treat us like a child. Treat us equally. Our diagnosis doesn't define us.

I'm not the same person. I will not be the same person. We can be unpredictable and that makes people upset. It can shatter family dreams – but we are the same people inside and please treat us with respect.

What's one thing people can do now? Go and talk to a person living with dementia about something that interests them. Please don't ask: do you remember me? Introduce yourself, tell us your story, find out what interests us.

Dialysis and older men, Max Primmer

Chronic kidney disease is more common that most people think. The prevalence increases rapidly with age, affecting around 44% of Australians aged 75+**.** For people on dialysis there are high rates of mental health issues and poor quality of life. The research also shows that although twice as many women than men on dialysis are diagnosed with depression - twice as many men suicide.

Men more often adopt avoidance as a coping strategy and can find it difficult to express their fears in response to the social pressure or expectation of them being tough, strong, and responsible for the economy of the household. This is the point I want to highlight. Older men have a different experience of dialysis – they can be marginalised by their mental health issues and the lack of information on how to adjust when they need dialysis.

Not enough people are donating their organs, so getting a kidney transplant is difficult and the reality is a lot of older men will need to be on dialysis for a very long time. Some think – I'm not doing this for 10 years; I would rather be dead.

We need to give older men information, education and support to help them adjust. They are not genderless. We can relieve the distress for them and their families. What's one thing people can do now? Talk to your doctor about your kidneys and how you can look after them and become an organ donor.

Ageing on a Farm, Maddie

My mother June is 96 and was a farmer; she still lives on a farm, 260 kms from the nearest city. The closest town has a declining population of 2000 and is 31 kms away, half of which is gravel road. June loves living on the farm. She sits on the front veranda and surveys the hills with the two-way radio going to hear what's happening on nearby farms.

When June had to hand over her driver's license, she really felt that loss of her independence. She still laments that she can't just drive into town and get what she wants. It was a massive change in her life. The loss of her driver's license meant loss of access, freedom and self-determination.

We cook her meals and have a cleaner who does some of the basic cleaning. My brother and his wife live in a separate house on the farm, and they visit every day, but she still feels lonely. The biggest issue for her is loneliness.

I spoke to a home and community care service, but they don't have much to offer if you don't need food or a cleaner. It would be great if they could coordinate transport, I would love to see a local minibus pick up older people and drive around. They could look at other farms who see who has sheep and what the crops are doing.

If I was to change one thing, I would say we need more social support, some kind of visitor's scheme to tackle the dreadful issue of loneliness of ageing on a farm. The visitors could help to alert family when things are not right. Mum is craving a scrabble buddy. A regular visitor would be ideal, she would look forward to someone coming – it would provide a little lift – and a motivation to do things, to keep moving.

Living with HIV, David Menadue

My name is David, I'm 70 years old and some days I feel like I am 86. I eat well and I exercise, but at the end of the day my HIV has made me age much quicker than I would have otherwise. We have great treatments for HIV now, but there are still problems with inflammation that cause some of us to age prematurely. We are more susceptible to things like osteoarthritis, heart disease and renal problems. There is a myth that HIV is 'fixed', but we are ageing prematurely, and so we are concerned about aged care.

People living with HIV were isolated in the 80s and 90s. They didn't want to come out because of the stigma and because it wasn't safe. They could lose everything. The stigma is still real. While we have reduced numbers of new HIV infections in Australia greatly because of new treatments to prevent and treat HIV better, there are still around 500 new infections a year and the number of heterosexuals living with HIV is growing. Around ½ the population of people living with HIV are over the age of 50, and this is when most people get comorbidities.

The stigma from service providers is a real problem. The *HIV Futures* research showed that for older HIV positive gay men, the greatest predictor of their self-rated wellbeing is whether they experience stigma and discrimination in services. In other words, the knowledge and attitudes of staff makes a real difference to our wellbeing. We need the aged care workforce to be educated.

One thing that people can do now is get some basic facts about HIV. The Living Positive webpage has great resources, include basic facts, which takes about 5 mins to read.

Homelessness - Chuping Yu's story, Housing for the Aged Action Group

Older people, and particularly older women, are becoming the new face of homelessness. Many older women live in severely overcrowded housing, unregistered and unregulated boarding houses, sleep in their cars, couch surf with family and friends or opt for other unsafe housing options before seeking help from homelessness services. This means many older women who are experiencing homelessness are not represented in official homelessness statistics.

Chuping, in her mid-50s, is a one of these women. It wasn't until she had been living a transient life for a number of years that she eventually sought support. She managed to keep a roof over her head by couch surfing with friends and house sitting. This arrangement worked well enough for a time. When the friend she was house sitting for entered into a new relationship, the new partner did not understand their friendship of 24 years which made Chuping's housing situation untenable. Chuping decided to move out to preserve the long-term friendship. These experiences led her to Housing for the Aged Action Group's (HAAG) Home at Last Service, where she was able to get help with a priority housing application. Chuping was offered a property and while initially apprehensive about living in a high-rise building, she is delighted to have a place of her own. Today she volunteers with HAAG and is advocating for better housing options for older people.

According to Anglicare Australia analysis, only 0.4% of available market listings in 2023 were affordable for a single older person in Australia in receipt of the Age Pension. HAAG is calling on the Federal Government to work with State and Territory Governments to build public and community housing for people 55 years and over who can't afford rent in the private rental market. This must include, at minimum, housing for nearly 260,000 older people who are renting in the lowest income households and already paying unaffordable rents, living in marginal housing and experiencing homelessness.

Listening to Auslan users - Older Deaf Community, Katrina Mynard

This paper refers to Older Deaf people who use Australian Sign Language (Auslan) to communicate. Overall the experiences of this group include:

- History of institutional abuse
- Deaf child born into hearing family
- Inaccessible mainstream services
- Poor English and digital literacy
- Lack of information/ resource materials in their language (Auslan)
- Own community as key source of information
- Interpreter shortages
- Been taken advantage of by others (including hearing family).

In relation to ageism and respect for older people – what needs to improve is:

- All community, government and service provide information in Auslan
- Auslan interpreting to be provided at all events
- Improved access to quality and reliable interpreting services
- Deaf Awareness Training for all students and workers.

One thing that people can do right now is try to keep the ask simple and include information on where to go for more. Introduce yourself to a Deaf person and ask them how they want information conveyed. Every project you develop, every information piece you create, every event you plan…ask yourself, is it accessible to a person whose first language is Auslan.

Older women paying the price, Yumi Lee, Older Women's Network NSW

I have the enormous privilege of working for an organisation which is committed to ensuring that older women can age with dignity. Sadly, based on ABS data, research and backed up by the type of calls we receive from older women seeking help, we know that this is a pipe dream for too many.

There are not many options available for older women who want to leave a violent relationship because there is just not enough affordable housing out there for them. Older women today are paying the price for decades of gender inequality which have resulted in poor savings, little superannuation and low pension payments. This is why many are falling into poverty and homelessness.

Over the past couple of years, my organisation has been working closely with Dr Catherine Barrett, the founder of Embolden and Celebrate Ageing, on raising awareness and calling for action to end the sexual assault of older women in aged care. Thanks to the Older Persons Advocacy Network, we have all worked together to develop resources for aged care providers to recognise, respond and prevent the sexual assaults in aged care.

The darkness of the work we do as an organisation is balanced by the incredible energy, wisdom and commitment of the older women I see on a daily basis. Some of them perform in our Theatre Group. They sing, dance and act out the human stories of these statistics of issues I mentioned above in ways which reach the heart like numbers never can.

What is one thing people can do now? Embrace the power you have to bring about change by joining with other like-minded people to act now for all the things you care about – whether it is climate change, injustice, ageism, sexism, etc. We are always stronger together and more powerful together. And if you're an older woman, join us! Web: www.ownnsw.org.au

Defence & LGBTIQ+ Veterans Suicide Royal Commission, Yvonne Sillett

My paper is referring to those ADF (Australian Defence force) veterans who have been discharged / downgraded due to their sexuality whilst serving their country. Prior to 1992 there was an archaic policy in place banning 'homosexuals' in the ADF. This meant that if it was discovered that members were 'gay' some would be tolerated (just) whilst others were discharged immediately, generally, after being psych tested.

In my own situation in 1989, after being interviewed (interrogated) for three hours on two separate occasions I was given the option to take an honourable discharge after my security clearance was downgraded from Top Secret to Confidential making me unemployable in the Corps of Signals, where I had been employed in for 10 years. However, there are other situations, where members were marched off base after being interviewed (interrogated) with no option whatsoever; it did not matter that they had nowhere to go and no communication with friends or families (other than public phone boxes).

On the 8th July 2021 it was announced that there would be a Royal Commission into Defence and Veterans suicide. This opened the door for many ex-members that had been suffering in silence with mental health issues for many years after they served in silence. It is with great hope that at the conclusion of the Royal Commission and when it comes to the final report in 2024 that the LGBTIQA+ veterans finally receive the apology that they deserve, just as the UK has done in recent months. I believe that it would also be appropriate if those members that lost their careers prematurely are given some form of reparation for loss of earnings and potentially a pension for life.

If you are an ex serving member of our community that was mistreated due to your sexuality or in fact in other regard, for example bullying and harassment, I implore you to reach out to DAVLS (Defence and Veterans Legal Service) who will guide you on the journey to tell your story to the Royal Commission. It is a free legal service that has been created purely to aide veterans in submitting their evidence.

Men who care, Dubhg Taylor

Dementia brings increased physical and emotional distress which can have a massive impact on even the strongest relationship. Sadly, there is little acknowledgment of the ways it affects care partners. I want to specifically address the topic of male care partners and the issue of intimacy.

Some men with a female partner who is no longer sexually interested may believe this is a reflection on their manhood and this can be a barrier to them talking to service providers about it. They may also be struggling with the issue of sexual consent – if their female partner is unresponsive, how do they know when to persist or how to negotiate sexual consent?

Male carers may be embarrassed or afraid to talk about what they are experiencing. It may feel too private or scary talking to a health practitioner – it's quite different to speaking with your mates over a pint of beer at the pub. The consequence of this situation is that one can feel lonely and frustrated and confused. How do we manage these situations? Typically, the biggest thing is loneliness.

About a year and a half ago, there was a program run by Dementia Australia for male carers, called *Blokes Who Care*, which was wonderful. Sadly, it didn't last long. We need to expand on this to form connections to help each other. We need to have carer groups for male carers to discuss issues that affect us, and we need to support each other. In mixed carer groups the men stay silent. If you are reading this and you know a male who is a care partner, let him know this: You are still a man. If your partner has dementia and their sexual interest or intimacy changes due to dementia; it's the dementia that has caused that, not your masculinity. You are still a man.

Dementia, masculinity and self-harm, Steve Grady

The misconceptions about people living with dementia is that we turn into raving lunatics and become abusive and do strange things until we turn into a vegetable or become silent. That's not how it is, but that misconception affects how we respond to the diagnosis of dementia. I want people to understand this – and that our responses to diagnosis are shaped by our gender.

For many older men, their idea of self is wound up around their work. What they are able to do helps to define who they are. Suddenly when you are diagnosed with dementia that's taken away from you. The doctor can say you are no longer able to work. It's a big struggle for us to adjust to that. Some men see the diagnosis of dementia as the loss of health and loss of their position of power and influence. The loss of health is the knowing that dementia is a progressive illness. The loss of power is the responses of others to the diagnosis of dementia.

In a world where shame and stigma mean we feel we can't talk about the diagnosis of dementia, and we can't talk about the changes to our perceptions of who we are as men – that's when self-harm happens. Some men try to kill themselves, or self-harm with drug or alcohol abuse due to loss of health and masculinity. I have been involved in research that showed when they get referred to mental health services, the prevalence of self-harm decreases.

Practitioners need to ask about what we are experiencing and link us in to support services. They need to understand that people living with dementia have gender, and our gender influences the ways we respond to dementia. It is ageist to think we are genderless.

What's one thing people can do now? If you are a person living with dementia -confront your fears. The earlier you get diagnosis, the earlier you can get support. If you are a service provider, ask us if dementia has changed the way we feel or express our gender. Then ask us what support we need.

Polio survivors: Shirley Glance OAM

Poliomyelitis or Polio was one of the most feared diseases in the world, paralysing hundreds of thousands of children every year and causing permanent muscular damage. The epidemic peaked with around 70,000+ Australians diagnosed between the 1930s-1960s. Most Polio Survivors are now aged 50+.

Children diagnosed with Polio were told they didn't have a disability or wouldn't have one unless we were lazy. There were few support services, so we just had to get on with living as best we could. People wanted Polio to go away, so we were taught to say nothing. We were silenced. We hid our disabilities and tried our best to live 'normal' lives.

Many Polio Survivors continue to live with symptoms and chronic conditions attributable to their original polio infection. Others can develop Post-Polio Syndrome (PPS) 40 years after contracting Polio. This is a degenerative disease causes muscle weakness and atrophy, chronic fatigue, pain and respiratory problems, sensitivity to cold, difficulties with swallowing and poor sleep. It has a significant effect on overall health and wellbeing, and the capacity for older adults with PPS to age well.

Several of the current issues we have stem from the lack of recognition of Polio as a disability. This has meant that many Polio Survivors have not accessed NDIS because they don't understand the limits they have as a disability. It has also meant that Polio Survivors are not accessing the supports they need to stay at home and so they are at risk of premature admission to residential aged care. Service providers need to understand that we were hidden from the public and so were our disabilities. So many of us were not 'allowed' to have a disability, and so even though we walk with a frame or callipers we may not see that as a disability, and we may not understand that aged care services have anything to offer us.

What's one thing people can do now? We want you to watch our film and then go to the AAG webpage and download our preconference workshop report. Workshop report: https://www.aag.asn.au/Web/Stay-Informed/Latest-News-Articles/AAG-report-on-Post-Polio-Syndrome.aspx

Ageing in Muslim Communities, Hayat Doughan

The teaching of Islam preaches honour and respect for older people and holds parents and grandparents in the highest esteem. Built on the tenets of care, dignity, compassion and kindness, Muslims are called upon to look after the ageing members of their families and communities. Islam does not consider the elderly as burdens on society but rather it recognises their past and continuing contributions to society and seeks to repay them by acknowledging the special status they deserve. The process of ageing itself is considered a blessing, a time for inner growth and introspection on the journey back to spiritual purity.

According to the 2021 Census, over 800,000 people in Australia identified as Muslim, an increase to 3.2% of the population from 2.6% in 2016. The Muslim diaspora in Australia is one of the most diverse representing numerous ethnicities, cultures, languages, and Islamic traditions.

Older people from Muslim backgrounds have many things in common with other communities from different cultural and religious backgrounds. Apart from sharing their migrant or refugee experience, many share the traumas caused by war or oppression and discrimination. The hardships brought on by these experiences can significantly impact peoples' health and wellbeing causing older people to become more vulnerable, and more dependent on their family members for support. There are also other issues that can impact on their vulnerability such as language barriers, lack of information about Australian systems and services and lack of health and digital literacy.

For older Muslims however, these issues can be further compounded by the fact that there are many misconceptions regarding Islam and preconceptions about Muslims which may influence the way others in the community interact with them. It is critical that service providers are mindful of the issues that may be affecting an older Muslim person, be open to understanding their experiences and needs, and ensure they are providing services which are culturally appropriate and inclusive.

What's something people can do now? Ask questions to learn about the older person, fostering choice and control, and active listening without judgement are all important ways of showing respect and ensuring that older Muslim people age safely and well.

Older (cisgender) women in the oldest profession, Rachael Brennan

There's raised eyebrows when I mention my research with sex worker women over 50 years of age. Concealing ourselves can be necessary in a hostile world. But invisibility also means that many layered social and systemic inequities persist.

Sex work is 'legalised' in Queensland, but unfortunately remains police regulated. At licensed brothels, sex workers are deemed to be independent contractors without workers' rights. We can work privately, but it's illegal to work in partnerships or cooperatives; we can't share premises, split costs, hire a receptionist or work together in any way.

My research with older sex worker women showed that regardless of participants' pride in their work there were many layers of discrimination they waded through. Barbara told me how the police wouldn't help her once they discovered her occupation. Kitty had her all her bank accounts closed when she declared her (legal) occupation. Kathy noted that declaring her occupation on tax returns meant she couldn't get a loan, buy a car, or rent a home. And courts have ruled that accommodation discrimination is permitted against those doing sex work in Queensland – leaving older sex workers particularly vulnerable.

Participants discussed how their work styles changed as they aged; for many work opportunities and earnings decreased. Often older, regular, or long-term clients became a more significant part of their work. At 64 herself, Princess kept seeing one client after he moved into aged care, providing not just a physical service, but intimacy, companionship and anticipation of a monthly date so meaningful to him.
As they aged, sex work often remained the best – or sometimes only – work option as participants found themselves managing disability or excluded from non-sex work jobs. But poverty, isolation, stigma, discrimination, combined with ageism and our society's failure to embrace ageing sexuality all makes sex work harder, and some older long-term sex workers experienced burnout and despair.

Decriminalisation is a critical first step towards workplace health and safety, and labour rights. But more work is needed to ensure that anti-discrimination protections are strengthened. And that the sexual and intimacy rights of older people are recognised as human rights, embedded in all aged care settings, including respecting older sex workers.

Ripplegrams and Trans and Gender Diverse people, Kathy Mansfield

There are increasing numbers of older people transitioning or living out their gender diversity in later life. The current generation of older people grew up with limited knowledge or choices for gender expression outside the gender binary. Many older people who thought they might be gender diverse early on in their lives, knew that disclosure could result in rejection, incarceration, or institutionalisation. As a result, many tried (unsuccessfully) to repress their gender diversity, many married and had children and are now embracing their gender diversity in their sixties seventies and eighties.
Valuable insights surfaced with funding of the Kinfolk project by the Australian Government Department of Health and Aged Care. I was fortunate to be a co-researcher on that project and developed a Ripplegram analysis tool, a process to help older people understand and adjust for the consequences of later life transition.
Older TGD people who are read as gender diverse are more vulnerable to violence and abuse. Making sure we are safe remains a constant and exhausting task. TGD people rarely receive equity, there are higher levels of poverty, poorer mental health, and higher rates of abuse – add ageism to that for older TGD people!!!

Ripplegrams demonstrate that there can be significant issues for adult children and married partners to adjust when an older family member transitions. Some family relationships fall apart, in other families there are restrictions on gender expression, including complete repression of gender identity. This unique form of Elder Abuse or Family Violence has escalated in recent times and is still not adequately recognised.

I want you all to understand our UN designated human rights are on the cusp of being threatened, even in Australia, by political forces using trans hate as a political / religious wedge. The gains we have made towards general community acceptance and support are at risk of being lost.

I want to ask people to read the Ripplegram report and think about how they can support older people who have reached a period in their lives when they know it's their last chance to be their authentic selves.

Sexual consent in the context of dementia, Theresa Flavin

While sexuality is as individual as the stars in the sky, there are a few common themes, the most fundamental of which is mutual consent.

In the context of relationships where one or both partners lives with dementia, there is often a marked difference in levels of sexual interest and willingness. For example, a person living with dementia may become hypersexual, sexually demanding and incapable of respecting a 'no' response. This will often result in repeated rape of the more sexually vulnerable partner. It's not uncommon for the less interested partner to use sexual activity as a way to placate the more interested partner in order to avoid violence. On the other hand, when the less dominant partner lives with dementia, it's also quite common for the more dominant partner to continue sexual activity in the absence of consent. Resulting in physical and emotional damage which goes unacknowledged.

In residential aged care, more dominant and sexually demonstrative people, without the insight to respect or request consent, assault other more vulnerable residents and staff. Resident-on-resident sexual assault is not well managed, as the nexus between respecting the human right to sexual expression and respecting the right to say no becomes cloudy.

I would suggest that a number of things to allow us some personal autonomy in our sex lives into the future, when we may no longer have the means or capacity to consent or respect the wishes of the other partner: co designed education, development of an 'advance social directive', mandatory reporting and trauma informed care.

Consider the resources developed by the #ReadyToListen Dementia and Sexual Assault Special Interest Group. Think about them in the context of your work. Could they be adapted? Could they be improved? Can your business consider a sexual health policy that includes the individual wishes and preferences of each individual older person and supports them in those wishes and preferences as opposed to a blanket ban on sexual activity or asking adult children for permission for the older person to have a sexual experience? Consider the role of specialist sex workers, pornography or other aids that may assist in the older person expressing their sexuality without the risk of imposing on another's human rights.

If you take away one thing from what I'm saying, let it be that the voice of the older person is what matters most, and whatever means we can employ to have that voice carried into the future and respected is the best and fairest way to go.

Concluding remarks

The inaugural Congress of Older People's Voices from the Margins provided an opportunity to learn from fifteen older people about how ageism has contributed to their marginalisation. It presented a broader understanding of diversity of older people's experiences and needs. It promoted an understanding of equity beyond ethnicity and racism to include other forms of oppression, such as ableism, sexism, metro centricity, classism and queerphobia.

Congress also provided an opportunity to explore how ageism is experienced by marginalised groups of older people.

The concept of marginalisation has much to offer approaches to diversity planning and programs to prevent Elder Abuse and other forms of ageism. It views marginalised older people as 'us' rather than 'them' - to guide an understanding that we all play a role in marginalisation and strategies for prevention.

Future work is required to explore narratives from additional groups of marginalised older people. Additionally, there is an opportunity to explore how marginalisation could be incorporated into diversity frameworks and strategies to improve their effectiveness.

It allowed many different stories to be told and it was beautiful to see the diversity of ageing.

The Embolden2023 Collection

celebrate ageing Ltd.

More information

Webpage:
celebrateageing.com/embolden
celebrateageing.com/margins