WINSTON CHURCHILL MEMORIAL TRUST

Walking in the Rainbow: Exploring inclusive aged care for the LGBTIQ+ community

Dr. Jane Youell

2017

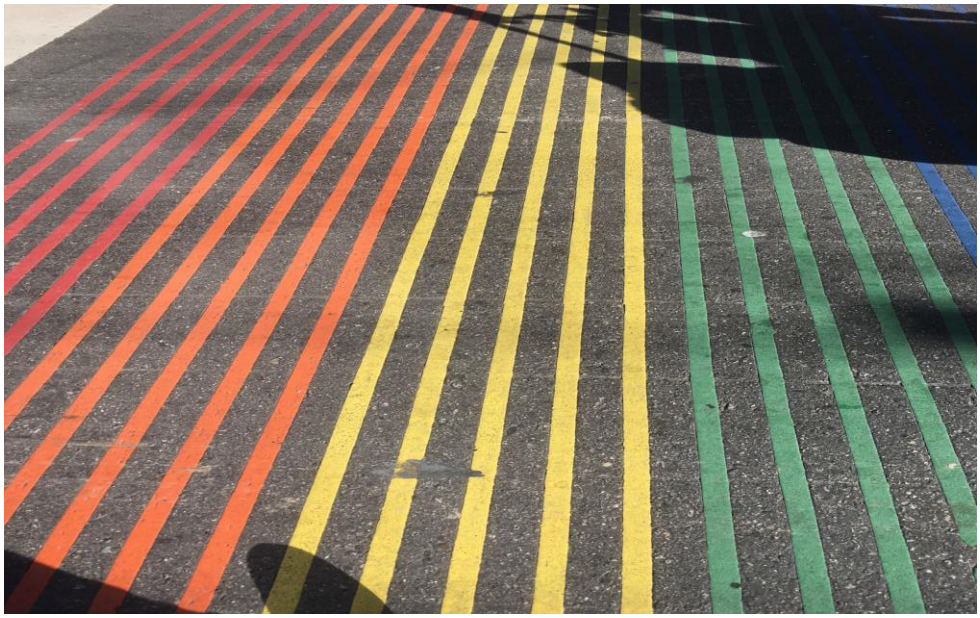

Figure 1 Rainbow Crossing, Castro District, San Francisco

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Acknowledgements

I would like to formally acknowledge the Winston Churchill Memorial Trust for funding my awfully big adventure and believing in my project.

Special thanks go to all those who I met on my journey. I cannot thank you enough for your support and for encouraging my work. The warm welcome and acceptance I received everywhere really made the trip very special. I still smile about some of the encounters I had and the stories I heard have influenced my thinking and practice in ways I had completely underestimated.

I would like to acknowledge the support of my dear friend and fellow Fellow, Dr. Alison Ward, without whom I would never have applied.

I would also like to thank my amazing family for their support, encouragement and managing to survive without me for a few weeks. May we all have lots more adventures and change the world.

Abbreviations

LGBTIQ+

> An inclusive acronym encompassing all minority sexual and gender identities, as well as atypical biological sex or Intersex. Trans* is inclusive of all transgender persons from transsexuals to transvestites, some of whom may identify as binary male or female, irrespective of biological/body sex and others as outside the binary of just two genders. Q+ includes all other identities including Asexual, Pansexual, Genderqueer, Non-binary, Questioning etc. People whose gender is non-conforming may also identify as LGB or another minority sexual identity, or they may identify as heterosexual. No disrespect or erasure is intended in not using one of the longer LGBTIQ2SA type initialisms or terms appropriate to different languages and cultures. There is no international agreement on how to extend LGBT to be more inclusive of all Gender and Sexual Diversities[1]

Dr Jane Youell CPsychol

Jane is a chartered psychologist and an experienced qualitative researcher with particular interests in dementia, autism, learning disability, end of life care, death and dying, family and relationships. She has a first-class honours degree in psychology and a PhD. Her doctoral work addressed the issue of intimacy, sexuality and dementia. Jane is a freelance researcher and consultant.

Jane has been commissioned to work with Dementia UK to develop a training programme to enable Admiral Nurses to better support couples living with dementia particularly in relation to intimacy and sexuality. Jane was the former Dementia Lead at Milton Keynes University Hospital and continues to work directly with patients and carers as part of her work with the UnityDEM project. Jane regularly lectures on the undergraduate nursing degree course and the Advanced Dementia Care masters course at the University of Northampton and is due to start a new role as Senior Research Fellow at the University of Leeds in the new year.

> *"Through my research work and my experiences in practice, I have become increasingly aware of the inequalities which exist in health and social care. I was consulted on the early work conducted by the Alzheimer's Society to develop a training resource around LGBTIQ+ communities and dementia care. During the course of these early consultations, through the people I met and the personal accounts I heard, I began to slowly realise that I had so much to learn, that whilst I can never fully appreciate what it is like to be LGBTIQ+, I needed to listen to the community and consider how I can better advocate, champion and ensure equality in the places I work, the teams I work with, the research I do and the individuals I care for. I am willing to learn and I welcome conversations with the LGBTIQ+ community and other professionals so that I might listen and understand the experiences of others."*

Executive Summary

The aim of this Churchill Fellowship was to better understand how aged care services could include and respond to the needs of the LGBTIQ+ community. I wanted to visit countries where I could find evidence of good practice in LGBTIQ+ aged care. I visited Adelaide, Melbourne and Sydney in Australia and San Francisco, Boston and New York in the USA. Three broad themes emerged from my conversations with the many and varied organisations I visited, that of *National Drive, Organisational Desire* and *Community Benefits and Good Practice.* The theme *National Drive* addressed the political commitment to improving aged care for the LGBTIQ+ community and how this enabled change through funding opportunities. *Organisational Desire* speaks of how organisations utilised training and quality improvement standards to create inclusive aged care environments. I witnessed many examples of good practice, often small considerations which made a big difference and the theme *Community Benefits and Good Practice* has tried to capture as many examples as possible. Next steps and recommendations include lobbying for mandatory cultural humility training, a greater understanding of the health disparities in aged care for the LGBTIQ+ community and how to address them and finding innovative ways to promote the needs of the older Rainbow community in partnership with older LGBTIQ+ people.

Figure 2 Rainbow flag flying in Harvey Milk Plaza, San Francisco

1. Introduction

Background

This report seeks to offer the highlights and findings of my recent Churchill Fellowship adventure. The findings suggest that a *National Drive* in the form of legislature and funding opportunities better supports an *Organisational Desire* which enables *Community Benefits*. I offer suggested proposals for how we might utilise these findings to improve the lived experience of older LGBTIQ+ people in the UK.

My Churchill Fellowship came about following my doctoral work which looked at sexuality, intimacy and dementia. All my participants were aged over 65, who were largely expected to be 'sexually retired' by aged care services and society in general. The findings from my doctoral research expressed a different view, that intimacy remained important into older age and despite the progression of dementia. I interviewed many couples and gathered their love stories, some more difficult to hear than others, which suggested that care plans often ruptured and disrupted the intimate relationship.

Whilst all the stories were poignant and often beautiful, one particular story shaped my thinking even further. One of my participants who I called Emily talked about her relationship with her husband. They were both 'second time arounders' having been widowed and divorced. She told me that she had children from her first marriage and that they had a child together although she wasn't sure how because they were not very sexually active. One day a couple of years into their marriage she walked into their bedroom and saw her husband dressed in Basque, stockings, high heels and a wig. She confided that she was shocked by this turn of events, that she did not understand why he would do this. The way they managed it in their relationship was that she pretended it never happened and he dressed up in private when she was not around. They continued their married life in this way for over forty-five years. Her husband later developed dementia and became increasingly difficult to care for at home. Emily, having had some nursing experience in her earlier life, believed she should care for him at home for as long as possible, but as his care needs increased she seemed uncharacteristically reluctant to accept that he might need residential nursing care. The reason for her reluctance was that he might try to dress as a woman in the care home. As a result, the last weeks and months of his life were an incredible strain on her and she coped extraordinarily through some difficult times. Her husband was eventually transferred to a nursing care home where he died within days of being admitted.

There are many stories which I carry with me, but this one in particular shaped my thinking. At the same time my son was coming of age. He has autism and a learning disability and I could see that he was wanting to date, just like any other late teen. We have carers who support us and it was obvious that some were more open to the fact that young people on the Spectrum should and could date, than others. His personal life was 'managed' and either supported or denied depending on the attitude of those caring for him. I began to realise that not everyone's private life is enabled, that for some in our society they were deemed too 'vulnerable' by others. Sometime later, my daughter came out and began a

committed relationship with another young girl. The narrative of Emily, my observations of care workers and my understanding of the Rainbow community through the eyes of my daughter made me rethink my doctoral work. Everyone identified as white and heterosexual who participated in my research project. My doctoral work highlighted that we do not really give enough thought to the impact of dementia in terms of intimacy and sexual expression, but now I began to wonder if we were failing older people who were identifying as 'mainstream', how were we meeting the needs of more diverse aged communities?

At around this time, I had been commissioned to deliver Tier 1 dementia awareness training in care homes and travelled across the South of England visiting various care home facilities. I began asking the care homes how many residents identified as LGBTIQ+. More often than not, the response was a long pause, then "None, dear". I began to realise that we were not offering sufficient safe spaces to talk about this, but also that it never really occurred to staff that residents would have a sexual identity and those who had considered it assumed that that identity would be heterosexual. I began to consider how might we create better inclusive aged care specifically for the older LGBTIQ+ community.

Stonewall (2017)[1] define an ally as 'being an active friend or support to someone else'. In their report Straight Allies (2011)[2] Ben Summerskill, then Chief Executive of Stonewall, states:

> 'Straight people have a critical role to play in creating gay-friendly workplaces. Stonewall Top 100 employers routinely tell us that 'straight allies' have been key to advancing fair treatment of their lesbian, gay and bisexual staff. Their involvement - often precisely because they're not gay themselves - can have a transformative effect on the culture of an organisation and the workplace experience of staff, both gay and straight.' (Stonewall, 2011, p. 1).

Stonewall also suggest that education and empowerment, listening, being visible, challenging bullying and inequality, influencing others and recognising intersectionality are the necessary steps to becoming an ally. It is within this framework of allyship with which I hope to influence those organisations with whom I hold any influence. I appreciate that I do not know everything and that I am early in this journey of understanding but I am willing to listen and learn and hope that this report can start some conversations around the topic of sexuality and intimacy in LGBTIQ+ aged care.

There have been important and significant legislative changes in recent years affecting the LGBTIQ+ community[3]. However, as the recent Stonewall (2018)[4] report finds there is still much work to be done. This report, *LBGT in Britain: Home and Communities* highlights that many people feel unable to be open about their sexuality and gender identity with family

[1] Stonewall (2017) Stand up as an Ally https://www.stonewall.org.uk/comeoutforLGBT/ally [Accessed 23rd Jan 2019]

[2] Stonewall (2011) Straight Allies: How they help create gay-friendly workplaces [Accessed 23rd Jan 2019]

[3] British Library (2017) LGBTQ Histories: A short history of LGBT rights in the UK [Accessed 23 Jan 2019]

[4] Stonewall (2018) LGBT in Britain: Home and Communities
https://www.stonewall.org.uk/sites/default/files/lgbt_in_britain_home_and_communities.pdf [Accessed 23rd Jan 2019]

members, that domestic violence is a significant problem which needs to be tackled more proactively, and that half of black, Asian and minority ethnic LGBTIQ+ people have experienced discrimination from others in the rainbow community. Discrimination against trans people within the community is also highlighted within this report as is that of the challenges of LGBTIQ+ people with disabilities. When considering the LGBTIQ+ community it is important to recognise the nuanced experiences of minorities within a minority.[5] These intersectionalities are defined as:

> "The various social identities, such as race, gender, sexuality, and class, which contribute to the specific type of systemic oppression and discrimination experienced by an individual."[6]

Ng (2016)[7] acknowledges that healthcare in general has been slow to recognise the importance of intersectionality and how this can affect and influence health related behaviours, access to health and social care services and mental and physical health. Ng (2016) argues that intersectionality offers a framework for a 'more comprehensive understanding of patients' health and healthcare needs' (p. 325). This perspective is echoed in the ethos of person-centred care which is advocated in health and social care services in the UK (SCIE, 2017).[8]

Sexual orientation and gender identity form an important basis of this comprehensive understanding of care recipients. The Centre for Policy (2016) review[9] of diversity in older LGBT people states that:

> "Relatively little is known, with any certainty, about the demographic composition of the LGB population in the United Kingdom. No question on sexual orientation was included in the 2011 census and most surveys of this population are purposive, self-selecting or convenience samples from which results cannot be readily generalised."

This lack of demographic information may lead to the assumption that I encountered in my informal poll in care homes and enhance a sense of invisibility.

One particular finding of the Home and Communities report, which is also relevant to the ageing LGBTIQ+ community is that of openness with faith organisations. Of the 5000+ respondents to the Stonewall survey, 32% of lesbian, gay and bi people kept their sexual orientation hidden from their faith communities. 25% of trans people were not open about their gender identity. 61% of those surveyed felt that their place of worship was not welcoming to LGBTIQ+ people with only 25% believing that trans people were welcome. This is particularly pertinent when you consider that many aged care homes are run and

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[5] Pannu, K. (2017) Privilege, Power and Pride: Intersectionality within the LGBT Community Available from https://impakter.com/privilege-power-and-pride-intersectionality-within-the-lgbt-community/ [Accessed 9th March 2019]

[6] Dictionary.com (2019) Intersectionality. Available from https://www.dictionary.com/browse/intersectionality [Accessed 8th March 2019]

[7] Ng, H. (2016) Intersectionality and Shared Decision Making in LGBTQ Health. *LGBT Health,* 1, 3, (5), 325-326

[8] SCIE (2017) Introduction to person centred care for older people in care homes. Available from https://www.scie.org.uk/person-centred-care/older-people-care-homes/introduction [Accessed 9th March 2019]

[9] Centre for Policy (2016) Diversity in Older Age – Older Lesbian, Gay and Bi-sexual People and Older Transgender People 2016 Rapid Review. Available from http://www.cpa.org.uk/information/reviews/CPA-Rapid-Review-Diversity-in-Older-Age-LGBT.pdf [Accessed 18th February 2019]

managed by faith-based organisations and that recognition of religious and spiritual needs are a requirement of the Health and Social Care Act (2008) as mentioned in the Care Quality Commission regulations for service providers and managers[10]

The LGBTIQ+ community have, and continue to experience discrimination and inequality in health and social care settings across the UK[11]. A recent Stonewall Health Report (2018)[12] highlights mental health as a significant health concern within the LGBTIQ+ community. Mind report that 1 in 6 people (16.6%) experience anxiety or depression at some time[13] In stark contrast, the Stonewall Health report found that 62% of LGBT people experienced or felt they had experienced depression in the last 12 months. This figure rose to 67% for trans people. Statistics relating to anxiety were equally disproportionately higher than the general population. Non-binary, bi, LGBTIQ+ youth and black and minority ethnic people also experienced a higher proportion of mental ill health. Levels of addiction, eating disorders, self-harm, suicidal ideation and attempts were also highlighted as significant concerns by the report. The reasons for these disparities are complex and include incidences of hate crime, harassment and violence, homophobic bullying and lack of access to LGBTIQ+ groups and support services (Stonewall, 2018). The recent Mind Out report, *Ageing Well in LGBTQ Communities*[14]*,* reports the higher rates of trauma experienced by the LGBTIQ+ community and the increased suicidal ideation when compared to the heterosexual population. The report argues that ageing adds further complexity to both metal and physical health and that older LGBTIQ+ people feel largely invisible and overlooked.

In support of this finding, one particularly relevant quote within the Stonewall Health Report (2018) is from Linda, 65 (Stonewall, 2018, p. 13)

> 'Until very recently, I seldom had a good relationship with health centre staff, GPs and nurses. It seems to me that it never occurs to many of them to ask for or be receptive to information about gender and sexuality so that they can factor this in when dealing with healthcare needs. I suggest much better training is required in some areas. I'm 65 now and this is a concern as I think about ageing and how people are treated in hospitals and in care homes.' Linda, 65 (Scotland)

When considering these inequalities in healthcare, it is perhaps easier to understand the reluctance of some LGBTIQ+ people coming out when going into residential care.

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[10] Care Quality Commission (2109) Regulation 9: Person Centred Care https://www.cqc.org.uk/guidance-providers/regulations-enforcement/regulation-9-person-centred-care#guidance [Accessed 4th February 2019]

[11] Mental Health Today (2018) Health and Social Care discrimination faced by LGBT people. https://www.mentalhealthtoday.co.uk/news/inequality/health-and-social-care-discrimination-faced-by-lgbt-people [Accessed 4th February 2019]

[12] Stonewall (2018) LGBT in Britain: Health Report https://www.stonewall.org.uk/sites/default/files/lgbt_in_britain_health.pdf [Accessed 4th February 2019]

[13] Mind (2013) Mental Health Facts and Statistics https://www.mind.org.uk/information-support/types-of-mental-health-problems/statistics-and-facts-about-mental-health/how-common-are-mental-health-problems/#.XGg3KC10c0o [Accessed 4th February 2019]

[14] Mind Out (2018) Ageing Well in LGBTQ Communities: Report on the need for recognition for LGBTQ 50+ Available at https://www.mindout.org.uk/wp-content/uploads/2018/05/ONLINE_LO-RES_Report-1.pdf [Accessed 9th March 2019]

Organisations need to be more proactive in ensuring that everyone in the communities they serve feels welcome and safe.

The State of the Adult Social Care Sector and Workforce in England[15] report (Skills for Care, 2018) states that 25% of the UK care home workforce are on zero hours contracts and that staff turnover is around 31%. Meeting the training needs of such a workforce is challenging. This report also found that the average age of a UK care worker is 43 with a quarter of the sector workforce being over 55. This means that the majority of the workforce were in education at the time of Section 28. Section 28 was an amendment to the Local Government Act 1988 which stated:

> A local authority shall not -
>
> (a) Intentionally promote homosexuality or publish material with the intention of promoting homosexuality.
> (b) Promote the teaching in any maintained school of the acceptability of homosexuality as a pretended family relationship.[16]

As Greenland and Nunney (2008)[17] write, this caused confusion for teachers who were unsure of what to teach for fear of 'promoting homosexuality'. The result was that 'this uncertainty led to teachers avoiding particular topics altogether' and 'it has been suggested that Section 28 has allowed homophobic bullying to persist and grow because it created an environment which failed to challenge and respond to homophobia' (Greenland & Nunney, 2008, p. 245). If Section 28 is the backdrop to the education delivered to the majority of the care sector workforce, there may be significant gaps in knowledge of the LGBTIQ+ community.

Age UK and Opening Doors London offer guidance and training around LBGTI+ aging and aged care. Age UK published their guide Safe to be me[18] which offers resources and guidance for professionals wishing to create an LGBTI+ inclusive service. Using examples of real-world scenarios this guide offers a checklist as a starting point to develop good practice and inclusive services. Opening Doors London (ODL) is the largest UK charity supporting the older LGBTIQ+ community. ODL offer a host of social events, a befriending scheme and advocacy for older LBGTIQ+ people as well as a several training courses for the health and social care workforce. Their mission is to provide:

> 'staff and volunteers with the knowledge and skills to enable older LGBT+ people to live happy, healthy and independent lives that are free from loneliness, isolation, prejudice and discrimination.'

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[15] Skills for Care (2018) The State of the Adult Social Care Sector and Workforce in England https://www.skillsforcare.org.uk/NMDS-SC-intelligence/Workforce-intelligence/documents/State-of-the-adult-social-care-sector/The-state-of-the-adult-social-care-sector-and-workforce-2018.pdf [Accessed 18th February 2019]

[16] Local Government Act 1988 *Ch. 9* Available at https://www.legislation.gov.uk/ukpga/1988/9/pdfs/ukpga_19880009_en.pdf [Accessed 18th February 2019]

[17] Greenland, K., & Nunney, R. (2008) *The Repeal of Section 28: It ain't over 'til it's over.* Pastoral Care in Education, 26:4, 243-251

[18] Age UK (2017) Safe to be me: Meeting the needs of older lesbian, gay, bisexual and transgender people using health and social care services. A resource pack for professionals. Available at https://www.ageuk.org.uk/globalassets/age-uk/documents/booklets/safe_to_be_me.pdf [Accessed 18th February 2019]

This work is much needed as the Stonewall Lesbian, Gay and Bisexual People in Later Life report (2011)[19] highlights the concerns and anxieties experienced by some older LGB people especially when accessing health and social care service provision. The report indicates that older LGB people are less likely to have children, more likely to live alone, more likely to be single and less likely to have regular contact with their biological families than heterosexuals. This is a significant finding when related to access to health and social care when significant others and/or family members would ordinarily support loved ones through assessments and transitions within the care system. Growing older alone is a more prevalent concern for some older LGB people, as is needing care, loss of independence, loss of mobility and poor health. The report shows the anxiety around finances and housing experienced by many older LGB people and the reliance on pensions for future planning. Again, this impacts on care decisions within the community. Bearing these factors in mind, the report recognises the need for older LGB people to be increasingly reliant on external support as they age. The report found that:

> 'Lesbian, gay and bisexual people are nearly twice as likely as their heterosexual peers to expect to rely on a range of external services as they get older, including GPs, health and social care services and paid help.' (Stonewall, 2011, p. 20)

The report also found that members of the LGB community experienced higher levels of anxiety around the need to use residential care home services. 70% of the LGB participants who responded to the report felt that they would 'not be able to be themselves if living in a care home and 65% felt that they would have to hide things about themselves from others' (Stonewall, 2011, p. 27).

There have been great strides in the LGBTIQ+ movement to gain legislative change, to promote equality and diversity in our society, to highlight the health disparities experienced by the rainbow community but there is still work to be done. As the 2015 Unhealthy Attitudes report[20] evidences both LGBT staff and patients experience bullying and discrimination and failings in support in health and social care. This report states that almost 60% of the 3001 health and social care staff included in this report felt that sexual orientation was not relevant when considering health and social care needs. The report concludes that organisations LGBT staff and patients should be supported in a person-centred way, that training and development needs should be identified and met and LGBT equality should be supported by health and social care providers. Whilst this report is not aged care specific, it is evident that the needs of the older LGBTIQ+ community need to be acknowledged, understood and welcomed by the residential care sector, especially in light of the historical context within which they have aged, the health and wellbeing concerns and specific anxieties around accessing institutional care.

[19] Stonewall (2011) Lesbian, Gay and Bisexual People in Later Life. Available at https://www.stonewall.org.uk/sites/default/files/LGB_people_in_Later_Life__2011_.pdf [Accessed 18th February, 2019]

[20] Stonewall (2015) Unhealthy Attitudes: The treatment of LGBT people within health and social care services. Available at https://www.stonewall.org.uk/sites/default/files/unhealthy_attitudes.pdf [Accessed 9th March 2019]

Aims, Objectives and Purpose

This Churchill Fellowship sought to better understand the work which was being done in Australia and the USA in this area, to appreciate the systems put in place and to talk to the local LGBTIQ+ community to understand the difference it made to their ageing journey.

My Churchill Fellowship was undertaken to enable me to better understand the needs of the older LGBTIQ+ community and the implementations organisations use to create inclusive aged care services. I wanted to better understand the processes of raising awareness of the needs of the older LGBTIQ+ community and how to get 'buy-in' from organisations who may be resistant to acknowledging this community. This report aims to provide insight into the ways in which effective change has been instigated in other countries, to propose evidence of good practice and to inform discussions around inclusive aged care.

I opted to travel to Australia and the USA with two key initiatives in mind. I was aware of an inclusive aged care initiative called the Rainbow Tick which offered organisations an accredited award for LGBTIQ+ inclusivity. I was also aware of the Fenway Institute and the work that they were doing around LGBT aging. These two initiatives were my starting point. As it was I was able to meet with a variety of organisations who were working hard to create inclusive aged care facilities and practices. I spent time with contacts from the care home sector, academics, psychiatrists, learning and teaching facilitators, diversity project managers, people living with dementia and their carers, gerontologists, psychologists, programme and policy managers, quality improvement specialists, directors of care management, researchers, advocates, government officials, community engagement programme managers, faith leaders, authors and film makers, community health workers and even a retired Judge. I had the privilege of being welcomed into several LGBTI friendly community groups and speaking with members about the things that concern them as they age. I learned so much and hope to capture the essence of that learning in this report.

Methodological Approach

I interviewed those I met using open ended questions around their service provision, ethos and what factors they felt needed to be in place to ensure inclusive care. I was fortunate enough to attend the 3rd LGBTI conference at the end of my trip to Australia which provided a greater appreciation and understanding of the Rainbow community, enabled further networking and gave me the opportunity to present my early findings. On returning to the UK, I transcribed the interviews and sought out patterns in the data using a simple thematic analysis approach.

2. Findings

This section will present the main findings based on the analysis of those who I met with and interviewed and on my observations of the community groups I attended.

It was a fascinating time to travel. As a backdrop to all the lovely inclusive work I could see was going on, the Australian Federal Government were holding a plebiscite, asking the Australian people to vote by post on the question of whether or not marriage equality should be brought into statute. To travel during this time, I bore witness to the discussions that were going on around equal marriage rights for all and realised that there was still so much work to be done around acceptance and the LGBTIQ+ community. It made people afraid and gave voice to homophobic rhetoric which was probably always there but now found an excuse to be heard.

Later as I travelled to the United States there was political and legal debate as to whether the trans community could continue to serve in the military. The Trump administration were not seen as LGBTIQ+ friendly by those I spoke with and there was real concern that this community would suffer in terms of rights and freedoms in the future. The older communities in both Australia and the USA were concerned about how their community were perceived which impacted on their care choices.

I was interested to discover the key components needed to bring about change in inclusive aged care. From my discussions and observations, three key elements influenced change that of *National Drive, Organisational Desire* and *Community Benefit.* The theme *National Drive* focuses on the impact of legislative change which came about to enable positive change. *Organisational Desire* highlights the crucial factors which need to be place for organisations to commit to inclusive aged care and the theme *Community Benefit* talks of the examples of good practice I witnessed whilst travelling in the hope that they may be adopted in the UK.

National Drive - the Australian Picture

In 2011 the Australian Government Productivity Commission[21] inquiry into aged care recognised LGBTIQ+ older people and made three important recommendations. The recommendations included accredited standards in health and social care services, access to appropriate information and assessment and workforce training to ensure the needs of diverse communities, including the LGBTIQ+ community are met. In response to this inquiry the Australian Government amended the Aged Care Act 1997 to include the LGBTIQ+ community as a special needs group[22]. In my discussions with those activists who argued for greater inclusive aged care at this time, the term special needs group was a slight point of contention, but generally the change in the Aged Care Act 1997 was welcomed.

With this change came a pledge in 2012 for $244 million in funding to help older Australians who were identified as a special needs group. In addition, the Government pledged a

[21] Productivity Commission 2011, *Caring for Older Australians*, Report No. 53, Final Inquiry Report, Canberra

[22] Explanatory Notes to the Aged Care Act 1997, Allocation Amendment (People with Special Needs) Principles 2012

further $2.5 million to fund specific training into the needs of the older LGBTIQ+ community and contracted an organisation to complete this work. The National LGBTI Ageing and Aged Care Strategy[23] was also launched in 2012. This Strategy, published by the Department of Health and Ageing, sought to recognise and promote the needs of older LGBTIQ+ people, to recognise their history and the impact this may have on their health and wellbeing. The Strategy acknowledged that older Australians had lived through an age when homosexuality was illegal, deemed a mental health disorder, where people could be (and still are[24]) subjected to 'curative' procedures, ostracised by family and friends and where careers could be lost. A history which is reminiscent of the UK, also. It is no wonder, perhaps, that we see a reluctance from older LGBTIQ+ people to be open about their sexual orientation, especially in healthcare settings.

The National LGBTI Ageing and Aged Care Strategy outlined actions to meet strategic goals and address LGBTIQ+ issues which culminated in a Living Longer Living Better[25] reform package which offered a framework for aged care organisations to embed LGBTIQ+ inclusive practices based on principles of inclusion, empowerment, access and equity, quality care and capacity building. Underpinning this work are the six strategic goals and actions set by the Department of Health and Ageing.

Goal 1 was to ensure that the LGBTIQ+ community experienced equitable access to appropriate aged care. To ensure this, the Government committed to including information on the needs of older LGBTIQ+ people in aged care publications and information, to ensure that inclusive aged care facilities were easily identifiable, that agencies and organisations use inclusive language in all resources, that inclusive practices maximise the health and wellbeing outcomes of older LGBTIQ+ people and to support those who are isolated due to geographical location.

Goal 2 was to ensure that the aged care sector proactively addressed the needs of older LGBTIQ+ people. The Government committed to make funding streams available to minimise social isolation, to ensure adequate access to advocacy services, to promote advanced care planning for older LGBTIQ+ people, to develop initiatives in dementia care which are responsive to diverse needs and to develop and evaluate programmes, projects and services which meet the goals of the Strategy.

Goal 3 was to support aged care organisations to deliver inclusive aged care. The Department of Health and Ageing pledged to include LGBTIQ+ people in organisational Standards, ensure organisations understand the need for legal protection against discrimination, that services are familiar with service delivery expectations, that complaints are included in awareness raising, that examples of good practice are shared and that support is given to implement the Strategy.

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[23] Commonwealth of Australia, 2012, *National Lesbian, Gay, Bisexual, Transgender and Intersex (LGBTI) Ageing and Aged Care Strategy*

[24] Gay & Lesbian Victoria & La Trobe University (2018) Preventing Harm, Promoting Justice: Responding to LGBT conversion therapy in Australia. Available from https://www.latrobe.edu.au/news/articles/2018/release/report-on-lgbt-conversion-therapy-harms [Accessed 9th March 2019]

[25] Aged Care (Living Longer Living Better) Act 2013, No 76. Available at: https://www.legislation.gov.au/Details/C2016C00170 (Accessed: 13 June 2018).

Goal 4 was to ensure the workforce were skilled and competent in delivering LGBTIQ+ inclusive aged care. Action points within this goal included support to develop policies, sensitivity training, increased inclusion of LGBTIQ+ issues in current vocational and tertiary training programmes, opportunities for professional development in LGBTIQ+ issues and that assessment teams are trained in inclusive practice.

Goal 5 was to encourage the LGBTIQ+ community to engage in the planning, delivery and evaluation of aged care policies and services. The Department of Health and Ageing pledged to empower older LGBTIQ+ people, their families and carers to ensure they receive appropriate services, support projects which empower older people, include representation from the LGBTIQ+ community on aged care decision making boards, to build partnerships between Federal Government, State Government, the LGBTIQ+ community and the aged care sector and to develop a communication plan to promote awareness of the National Strategy.

Goal 6 was ensuring that the LGBTIQ+ community were an aged care research priority. The Department of Health and Ageing pledged to increase the knowledge base around health and wellbeing for the LGBTIQ+ community, to identify indicators for inclusive care, to promote opportunities for research and to evaluate projects specific to LGBTIQ+ people.

This was a five-year strategy which was introduced under a Labour Government but continued under a Liberal one. Funding was seen as a key anchor in developing the ambitions of the Strategy. Whilst there was a sense that the Strategy had raised awareness and kick started some good work, the real impact of the Strategy was hard to measure and evaluate.

At around the same time as the National LGBTI Ageing and Aged Care Strategy was being developed, the Federal Government amended the Sex Discrimination Act 1984 to include a clause that stated you could not discriminate against anyone on the basis of their sexual orientation, their gender identity or their intersex status. In the amendment exemptions were removed to ensure that aged care providers could no longer discriminate on religious grounds. Whilst this reform was welcomed, the exemptions did not protect employees of these facilities from discrimination which is an important point. If we are to cater for diversity in our communities, then staff should also reflect that diversity.

The little that I understood of the Australian political system highlighted the need for LGBTIQ+ rights, policies and guidance to be bipartisan reforms. It seemed to me that the Federal Government repeatedly hung in the balance, often with only one seat in it so opposing parties came in and out of power. One interviewee felt that there was a 'certain amount of political football around social justice, aged care and the LGBTI community particularly'. Whilst some felt these Federal changes were something of a golden age in terms of reform, all agreed that there was still more work to be done.

It was evident from my discussions with those identifing as LGBTIQ+ and their allies that there was diversity within diversity. Some agencies I spoke with felt that there were not many laws supporting trans people at either State or Federal level and that there was still some disparity between States in Australia around legal protection for trans people. The

majority of work seemed to be focused on young trans people a particular example being the Safe Schools programme. The Safe Schools programme was an optional resource for schools and teachers which was available across States in Australia. The programme aims to provide professional development for secondary school teachers so that they feel better equipped to support LBGTI students. It was generally perceived by the LGBTIQ+ community that this was very good programme. In the run up to the plebiscite and during the plebiscite, the Safe Schools programme garnered much negative press with many States no longer running the programme. This sent a clear message to the older LGBTIQ+ community who were increasingly anxious about the outcome of the plebiscite during my stay in Australia. The 'Yes' vote won by clear majority (61.6%)[26] which led to the legalisation of same-sex marriage in Australia, but the discussions which were had at the time were ulterior evidence that there was still strong feeling around equality particularly for members of the LGBTIQ+ community. Many of the older people I spoke with felt at this time that the political climate was very reminiscent of the work they had to do in the 60s, 70s and 80s. On the one hand, organisations were claiming it was safe to be 'out' but nationally a debate was still raging around marriage equality.

Despite the complexities of the political climate during my visit, all organisations I met with felt that the changes to the Aged Care Act helped to drive the inclusive social care which is still emerging. It was felt that legislative reform was the single biggest driver to bring about positive change.

National Drive - a USA Perspective

I visited San Francisco, Boston and New York during my USA tour, as with my Australia leg I was seeking examples of good practice in inclusive aged care. In support of the theme which emerged around legislation, this seemed to be mirrored to some extent in the US. I spoke with organisations about State legislature which had positively impacted on inclusive aged care. It was felt that in Boston marriage equality, which was legalised in Massachusetts in 2004, gave greater credence and momentum to inclusive work. This was a State-wide policy and not national but created a cultural shift and enabled larger conversations to take place. It would be another 11 years until the Supreme Court sanctioned marriage equality and so Massachusetts was a prime State to visit as they were already advanced in terms of LGBTIQ+ inclusion. There was also concern that the Trump administration might undo a lot of positive work in this community. I had several discussions with people from the LGBTIQ+ community who talked of the strong religious right movement in the US who often funded and provided aged care facilities and services. There had been an increase in religious refusal policies which effectively gave licence for organisations to refuse to hire or serve people based on religious grounds. These organisations were/are very focused on sex and gender being fixed at birth and cannot be changed which obviously has connotations in service provision for the trans community. It was felt that the Trump administration were implementing a lot of policies which facilitated this attitude. Whilst in the US I bore witness to discussions around allowing the trans community to continue to serve in the armed forces, for example.

[26] Australian Bureau of Statistics, 2018, *1800.0 - Australian Marriage Law Postal Survey, 2017, National Results.* Available at: http://www.abs.gov.au/ausstats/abs@.nsf/mf/1800.0 (Accessed: 13 June 2018)

In San Francisco the Human Rights Commission had created an LGBTIQ+ advisory group which has been established since 1975. A taskforce was created to work with city elders but this work was largely disrupted by the AIDS epidemic. Work in this area is again developing momentum with a focus on better housing and supporting existing organisations to become LGBTIQ+ inclusive/friendly. In San Francisco housing is at a premium which was having a significant impact on the care choices of older people including the LGBTIQ+ community. Many service providers explained that older members of the LGBTIQ+ community were trying to move back into San Francisco as they had a nostalgic notion that it would be a great place to return to and retire. The State has encouraged large corporations and tech companies to establish in the region which has altered the housing landscape and impacted on the community. There is an increase in landlords encouraging older people to move on to make way for the influx of a younger workforce. I heard examples of an older person dying as named primary tenant, which meant that their life partner could not stay on in the home because their name was not on the lease. A situation which is not often realised by the community, until they experience the death of a partner. I met members of the LGBTIQ+ community who explained that they felt they were not well connected, that they had lost a lot of their support network due to the AIDS epidemic, had lost their partners and were now facing eviction and possible homelessness. For many they felt displaced and isolated.

Homelessness was evident and clearly an issue in San Francisco. According to a Department of Homelessness and Support Housing study, 30% of homeless people in San Francisco self-identified as LGBTIQ+[27]. There were significant numbers of older homeless people living on the streets at the time of my visit. Support agencies explained that there was an assumption that Medicare would take care of health expenses in ageing but this is often not the case. Older people were encouraged to remain in their own homes by support services as there was very little affordable aged care provision. There seemed a real disparity between expectations in older age and the reality. I heard a particular account of a couple who lived in a rent-controlled apartment one of whom had a good pension, the other was on MediCal (health insurance). Due the differences in their provision they would not easily be able to be placed together if they required residential nursing care. Many of the older buildings in San Francisco were not disabled friendly, often there were lots of steps up to apartments and the elevators didn't always work. This in turn led to isolation for many couples who felt 'trapped' in their apartments and unable to move because of the lack of alternative affordable accommodation. Housing was also an issue in Boston. Whilst affordable housing seemed to be an issue across the board, agencies were working with town planners to develop LGBTIQ+ friendly senior housing opportunities.

There are no definitive statistics in the UK as to how many older people, who identify as LGBTIQ+, receive care. This data is not routinely gathered by care providers. Anecdotally, healthcare professionals report that asking about a care recipients sexual orientation feels like prying and a little uncomfortable. When in Boston I heard of the drive by the State to ensure this information was gathered.

[27] ASR (2017) San Francisco Homeless Count and Survey Comprehensive Report 2017

"The State is now requiring us as part of our initial assessments to inquire about sexual orientation and gender identity and that was met with much gnashing of teeth and anxiety on the part of the case managers and nurses because of the existence of the LGBT aging project and its focus on training there was the ability of the State to offer all of us the training that was necessary to mitigate a lot of that anxiety." *(CEO, Ethos, 2018)*

In both Australia and USA, the legislative change led to significant funding being released to train staff working in the aged care sector to become more culturally competent and to ensure organisations were supportive and welcoming to the LGBTIQ+ community.

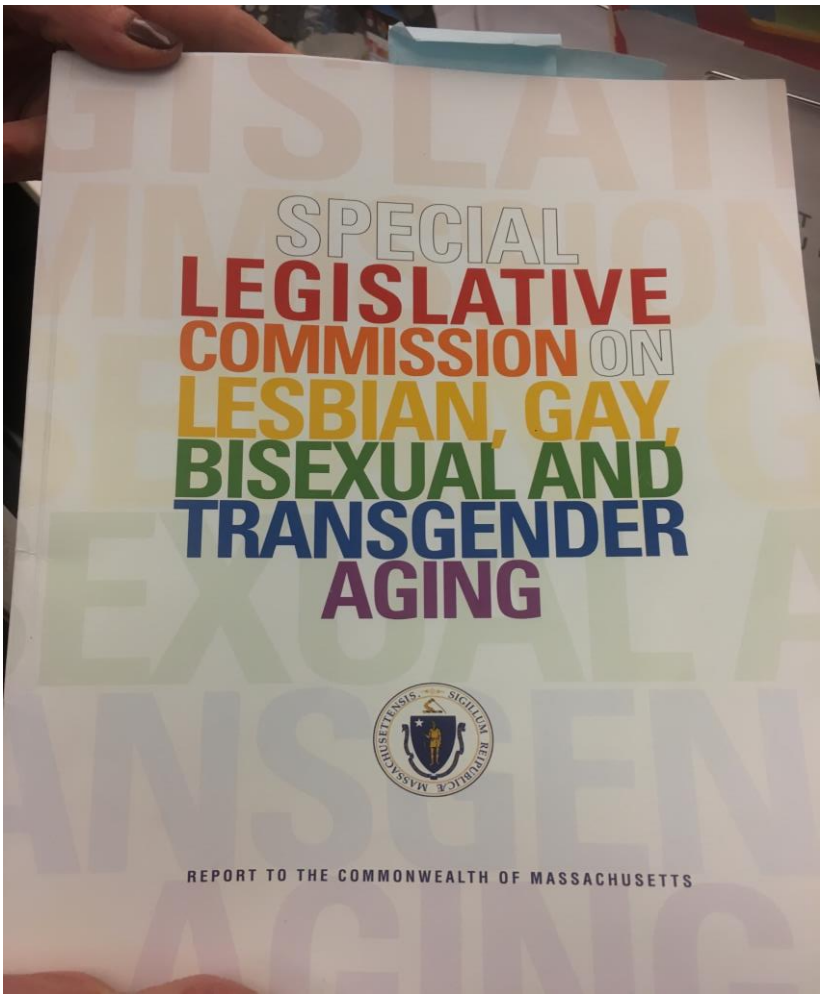

Figure 3 Massachusetts LGBT Aging Commission Report 2015

Organisational Desire

> "We are only being invited into their home, we do not live here, they do." *(Interview with care manager of large residential nursing home)*

I was particularly keen to understand what factors needed to be in place to create an organisational desire to become culturally competent and LGBTIQ+ inclusive and how organisations put this into practice. The framework of this theme is made up of strong leadership, accreditation and accountability and visibility. I was particularly interested in how faith-based service providers responded to creating LGBTIQ+ friendly services.

A common theme between the organisations I met with, both in Australia and the USA, was that of strong and committed leadership. Instigating a cultural change came from the top, with CEOs embracing the idea of inclusive care and ensuring this was implemented organisation wide. This was often not an easy transition for some organisations, especially the faith-based service providers. I heard accounts of how there were many discussions and interpretations of Bible readings in the early conversations around LGBTIQ+ inclusive aged care. Strong and committed leadership was crucial to navigating organisations through these discussions.

Integral to cultural change is training. All the organisations I met with either received cultural competency training, in the case of residential care facilities and service providers or offered cultural competency training. Cultural competency training seemed the most widely used term, but I also heard the term cultural humility. For me, competency implies there is an end point, that once you have been through the training you are therefore competent but I am not sure that this conveys quite the right tenet. I feel that cultural humility implies an attitude, a space where learning is ongoing and not finite. For the purposes of this report, I shall use the phrase cultural competency as this is how the training was identified, but for my ongoing work in this space I think I prefer cultural humility as a banner.

Interviewees talked about how cultural competency was about taking their own biases and acknowledging their own feelings about intimacy and ageing, about the LGBTIQ+ community and their own cultural backgrounds and how this may influence their values. I heard from one particular interviewee who came out as a lesbian after her marriage ended in divorce, she had children and the assumption was that she was heterosexual. When she disclosed her sexual orientation staff from countries where homosexuality remained illegal, was socially unaccepted, or seen as sinful, would assure her that they would 'keep her secret because they didn't want anything bad to happen.' Having an appreciation of the cultural backgrounds of both residents and staff is important in order to create a community where everyone feels valued, appreciated and celebrated.

This type of cultural competency training was not mandatory in most organisations and thinking of the care home settings I was familiar with in the UK, I could imagine that getting non-mandatory training into care homes where resources were limited would be a

challenge. What I realised when working with organisations in Australia and the USA that taking this approach enabled greater organisational buy-in because it was not just focused on the LGBTIQ+ community but included culturally and linguistically diverse (CALD) communities, the disabled community, etc.

> "It wasn't about Rainbow Tick we sometimes get lost in that, it's another label, it is a symbol, you know we are a welcoming inclusive organisation but for those of us who were really passionate about this issue more broadly, it was about inclusive practice. It doesn't matter if you put an LGBTI lens on it or you put a CALD lens on it, you put any other lens on it, it's all about being inclusive." *(Interview with Learning and Development Lead)*

The primary reason for choosing to visit Australia was to discover more about the Rainbow Tick accreditation. The Rainbow Tick programme was developed by GLHV (Gay and Lesbian Health Victoria) in response to a growing need from the LGBTIQ+ community for information about inclusive health and social care services and from organisations seeking ways to improve their quality of care for the LGBTIQ+ community. It was seen as a move away from being LGBTI friendly and more towards being LGBTIQ+ inclusive. The Rainbow Tick is an accredited award based on a set of Standards and quality indicators. Organisations receiving the Rainbow Tick accreditation are independently assessed by QIP (Quality Innovation Performance) to ensure that organisations show evidence of their commitment to provide inclusive, quality services for the LGBTIQ+ community. GLHV are funded by the Victorian State Government, it was felt that Victoria was more proactive and progressive than some other Australians States, which may explain why this work had developed here. GLVH sits within the Australian Research Centre in Sex, Health and Society (ARCSHS) at La Trobe University.

GLHVs focus is around sexual health and ageing, LGBTIQ+ inclusive practice and working with young people who are same-sex attracted and sex and gender diverse. Under the GLHV umbrella sits Val's Café, which is not a place to get coffee and cake at all, but a LGBTIQ+ ageing and aged care programme with a specific remit to promote care pathways and raise issues affecting LGBTIQ+ elders. What struck me with this structure was the networking and connectedness of academics, training facilitators and community members.

The Rainbow Tick accreditation was first piloted in 2012 with the first organisations being accredited in 2013. Of the four initial sites to pilot the programme, two gained accreditations. At the time of my visit 35 organisations were going through the process or had been accredited. It was generally felt that organisations are over regulated and that Rainbow Tick was competing against mandatory accreditation. This can be expensive for organisations.

The Rainbow Tick programme is made up of six Standards as follows[28]:

1. Organisational Capability
2. Workforce Development
3. Consumer Participation
4. A Welcoming and Accessible Environment
5. Disclosure and Documentation
6. Culturally Safe and Acceptable Services

Under each Standard are clear quality indicators which must be met to ensure that the Standards are culturally embedded within the organisation. Organisations who sign up for the Rainbow Tick accreditation can expect the process to take approximately 18 - 24 months to navigate the programme which is indicative of how the programme aims to ensure a cultural change and embeddedness. Once an organisation has completed the programme and has evidence of their quality improvement for the LGBTIQ+ community, they are subjected to an audit by Quality Innovation Performance (QIP). QIP are a third party approved accreditation body working in health and social care settings who are licenced by GLHV to accredit those organisations working towards the Rainbow Tick programme. QIP works with organisations to make sure they are supported through the process of obtaining the Standards set in the Rainbow Tick programme. When an organisation is ready for audit, QIP sent assessors out to the organisation to work with staff and residents, if successful the organisation receives a Rainbow Tick award for three years. The limited time ensures that LGBTIQ+ inclusive services are maintained on a rolling basis. Organisations who are already Rainbow Tick accredited are expected to show evidence of how they are continuing to develop this work in their ongoing business plans. Thus, ensuring a long-term organisational commitment.

[28] GLHV@ARCSHS, La Trobe University (2016) The Rainbow Tick guide to LGBTI-inclusive practice.

Figure 4 Accredited Organisations display rainbow welcome to visitors

Not all organisations are ready for such a commitment and so can undertake the How 2… programme which is a forerunner to Rainbow Tick accreditation. This training programme invites organisations to consider how LGBTIQ+ inclusive they currently are and where changes can be made to promote inclusive health and social care. The Rainbow Tick and How 2… programmes were not specifically designed for aged care but benefitted from the legislative change which was occurring at the time with the development of the LGBTIQ+ health strategy.

Early criticism of the Rainbow Tick was that it saw the LGBTIQ+ community as one homogenous group and that greater thought needed to be given to the unique populations within this community. More consideration needed to be given to differing life stages, intersections and health disparities. More has been included around the trans and intersex community in the second iteration. The organisations I met with who had been Rainbow Tick accredited reported that it was a very prolonged, expensive but rewarding process.

In the UK, Stonewall have been offering a similar programme since 2001. Their Diversity Champions Programme aims to work with employers to ensure that all LBGTIQ+ staff are welcomed and accepted in the workplace. Similarly, to the Rainbow Tick accreditation, organisations who participate in the Diversity Champions programme can utilise the Workplace Equality Index which is a benchmarking tool that offers indicators of what is working within the organisation and where some improvements in terms of LGBTIQ+ equality could be made. A Top 100 employers list is compiled each year which identifies high performing organisations and individuals. The Diversity Champions Programme is available to any organisation who chooses to engage and has not targeted one particular

sector as Rainbow Tick has done. As with the Rainbow Tick accreditation, the Diversity Champions Programme encourages organisations to continue to embed a culture of inclusion through an action plan and the use of Stonewall resources in best practice, developing policy and guidance and allies and role models.

The programmes that I saw in the USA were more grass roots and community based. Most training providers and lobbying groups were trying to upskill existing services as opposed to creating exclusive LGBTIQ+ services. The work of OpenHouse in San Francisco and the Fenway Institute in Boston were more community-based, offering social opportunities such as lunch and dinner clubs and peer support groups. Further discussion around this grass roots work can be found in the *Community Benefits* section.

In both Australia and the USA, I saw evidence of LGBTIQ+ awareness in all aspects of their organisation's functions. This included reviewing all internal policies, guidance and communication to ensure that their literature was not gendered and that appropriate pro-nouns were used at all times to promote inclusion. Many organisations made it clear in job advertisements that they were LGBTIQ+ inclusive and inductions included mandatory LGBTIQ+ training. Reviews of photographs used in organisational media were undertaken to ensure a representative sample of society and a move away from a heteronormative depiction. Emails were signed off with a statement acknowledging the inclusive ethos of the organisation. Sexual identity and orientation were mentioned in assessments in order for appropriate care plans to be made. Members of the LGBTIQ+ community were involved in all levels of decision making and allyships were formed. It was often time-consuming work but essential to embedding that culture of inclusion.

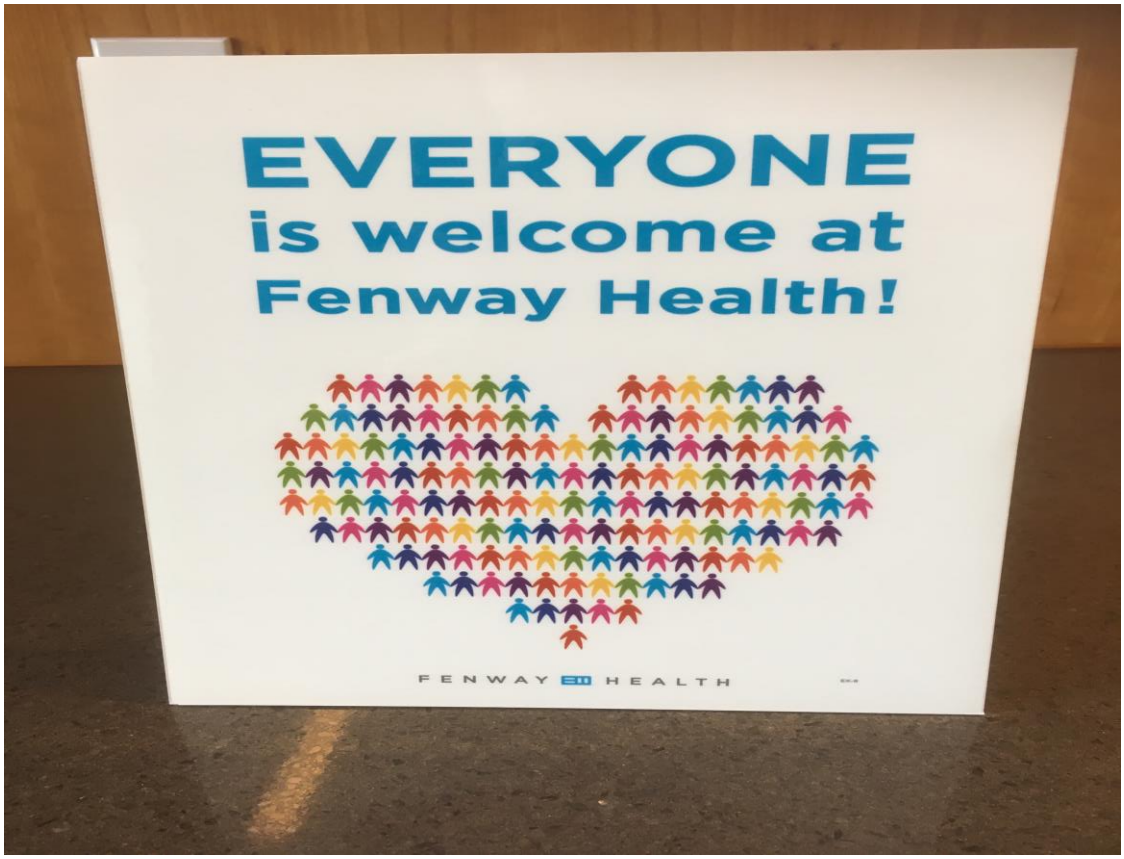

Figure 5 Fenway Institute, Boston, welcome sign

Community Benefits and Examples of Good Practice

Before travelling, I naively thought that I understood some of the concerns that the older LGBTIQ+ community might have, especially in a health and social care context. I understood that this was a generation who had lived through a time where homosexuality was illegal, a crime for which you could serve time in prison. I understood that same sex attraction had at one time been regarded as a mental health condition which often led to 'curative' therapies being put in place - a practice which continues in the UK today as evidenced in the recent Government Equalities Office, LGBT Action Plan[29] [30]. I thought I had some appreciation of the stigma and anxiety about being 'out' as an older person. But there was so much I had not understood.

Following my Fellowship, I began to appreciate the nuanced challenges facing older LGBTIQ+ people. I spoke with older people who explained their reluctance to engage with health care facilities for fear of being judged, who often hid their relational status from their healthcare practitioners, who during home visits would hide photos depicting their private

[29] Government Equalities Office (2018) LGBT Action Plan Improving the Lives of Lesbian, Gay, Bisexual and Transgender People. Available at https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/721367/GEO-LGBT-Action-Plan.pdf [Accessed 9th March 2019]

[30] Guardian (2018) 'I still have flashbacks': the 'global epidemic' of LGBT conversion therapy. Available at https://www.theguardian.com/world/2018/aug/08/i-still-have-flashbacks-the-global-epidemic-of-lgbt-conversion-therapy [Accessed 9th March 2019]

life and those they love. I hadn't fully appreciated the level of trauma that had been experienced and how having an understanding and acceptance for personal histories was so important in aged care practice.

"Everlasting impact comes from good relationships. The relationship IS everything." *(Interview with Resident Services Manager)*

Figure 6 Uniting, Sydney, Community Office welcome sign

Sexuality and intimacy are often problematised and 'managed' in older aged care. It is often a double whammy of being older and therefore the implication is that you should be 'sexually retired', if you have a mild cognitive impairment, disability or dementia then you 'shouldn't' be having sex are often assumptions held by care staff which enables stigma around older aged sexuality and intimacy. When considering the LGBTIQ+ community this seems to add an extra complexity which might be due to lack of understanding and engagement with the community.

Being able to see the perspective of the person in care in a non-judgmental way is vital in inclusive aged care. I heard countless stories of bad examples of care but with a little shift of perspective and understanding in many cases these need not have such a negative outcome. I heard one account of a resident who was an older man. He masturbated every time he showered, much to the distress of care workers who insisted on an investigation. It was later realised that because he wore pads during the day and at night, the only time he

could touch himself was when he was being showered. The solution was to remove the pad for a limited time in the evening and allow him some private time.

I also heard accounts of sex workers being introduced into care homes who specialised in disabled clients. This was an interesting perspective and one which already exists in the UK too. I understood that the Australian organisations offering this service in the words of my interviewee "they do it right, gently". This is certainly an option to address the intimacy needs of older people but should not be seen as an alternative to finding longer-term relationships.

One of the most interesting aspects of my Fellowship work, especially in Australia was the initiatives which promoted sustainability and celebration for minorities within minorities. I heard of Yarning Circles which were safe, harmonious spaces where indigenous elders share stories and support. Yarning Circles have been used to promote the interests of lesbian Aboriginal women. This is a fascinating way in which to engage with minority groups, to sit and listen to their experiences and one in which we can learn about and share health information.

Through my discussions I was able to better understand the health risks and concerns of the different groups within an ageing LGBTIQ+ community. I developed a greater appreciation of the mental health risks of older community members and increased suicide risk. I began to appreciate that there were nuanced differences in health outcomes for women. One group of lesbian women I met with reported that women who did not have children and were in a same sex relationship, would probably not use an oral contraceptive. This had implications in terms of their cancer risk. Michels, et al, (2018)[31] report that women who have never used oral contraception have a 30% increased risk of endometrial cancer, further research found that ovarian and breast cancer risk was also reduced in those who took oral contraceptives.[32] I also better understood that PAP screening and prostate checks should be offered to members of the trans community and wondered if this was effectively and sensitively managed in the UK.

One particular faith-based organisation, Uniting, felt that a key factor in inclusive work, particularly with the LGBTIQ+ community, was to create cultural safety points. They appreciated that older members of the LGBTIQ+ community were not coming to Uniting for their care needs because they had been discriminated against the whole of their lives, whether that be from a criminal point of view, or from a health or societal or religious perspective. The Uniting strategy was to look at how to make the organisation credible with the LGBTIQ+ community. Their commitment to the Rainbow Tick accreditation was part of this but so was the Australian Workplace Equality Index (AWEI). AWEI are a national benchmark for LGBTIQ+ workplace inclusion. Uniting felt that Rainbow Tick held credibility with clients, whereas, AWEI held credibility with employees and both were equally

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[31] Michels KA, Pfeiffer RM, Brinton LA, Trabert B. (2018) Modification of the associations between duration of oral contraceptive use and ovarian, endometrial, breast, and colorectal cancers. *JAMA Oncology*, 1, 4, (4), 516-521

[32] NIH National Cancer Institute Oral Contraceptives and Cancer Risk. Available from https://www.cancer.gov/about-cancer/causes-prevention/risk/hormones/oral-contraceptives-fact-sheet#r18 [Accessed 9th March 2019]

important to the organisation. The strategy in achieving high quality, inclusive care was to say it loud and in public and to be held accountable for its success or failure. This was seen as a key point that for a community who were not out, for an organisation to be public in its support for this community. Uniting utilised the catchphrase 'We come out so you don't have to', it was about recognising the cultural safety needs of the community. This was often work which was slow to develop but trust eventually built for the organisation.

"What is on the doors, what books do you have on your shelves, pictures on the wall, the badges for staff, reception centre will have stickers on the door and a poster when you walk in, staff have a rainbow badge. That's enough that you have a leaning for that, as a gay man I want to see more. There could be lots of people behind that door that would not be ok. It can feel a bit tokenistic, but is one stage, what you can see before you speak. You can't fake it, the LGBTI community are very attuned to whether or not it is safe to say anything. It's like an innate safety antenna." *(Interview with older gay man, Melbourne, 2017)*

Having discussed the ethos of Uniting and the strategies they put in place to become more inclusive I was interested in how this translated in practice. I was fortunate enough to meet an older lesbian, Bernette who recounted her experience of accessing care with Uniting.

"I hoped there would be some sort of level of acceptance and I kept quiet, you know and it was the reverse. When I said to the manager "Oh by the way, I've got a woman in my life", I thought I have to say it you know, it's no good her dropping in and out, you know. And she [the manager] said "Oh congratulations!" I nearly fell over, I almost was in tears I was so excited. The recreational manager said 'do you want to go to Mardi Gras? I'll organise transport for you. Photo came back of the march and the manager said "Where do you want to hang it?" and I thought I would have to put it up in my room and she said "Oh no, we'll put it up in the corridor where everyone can see it" and it's got my name on it so… So, the good part is that I now feel I have an identity that I always used to have."
(Interview with older lesbian, Uniting Aged Care, Sydney, 2017)

Figure 7 Uniting team with responsibility for Rainbow Tick accreditation

In San Francisco and Boston, I began to appreciate the importance of intersectionality and the LGBITQ+ community. I met with younger gay men who talked of the pressure they felt to be part of a youth focused community and how this precluded them from talking about their concerns and fears around getting older and what care needs they might have. I spoke with academics who were looking at post traumatic stress disorder (PTSD) as a risk factor of dementia and how this was particularly relevant to the LBGTIQ+ community as they are at significantly greater risk of trauma.

My travels and meetings focused less on dementia care and more on aged care generally, but I was fortunate enough to meet with the Alzheimer's Association in San Francisco where I learned about LGBTIQ+ dementia training which was offered in partnership with OpenHouse and the Family Caregiver Alliance. There were concerns that organisations often turned to online training as this was easy to access but that staff often didn't value this kind of training. Face to face training was seen as the space where real learning happens especially around cultural humility. An interesting statistic to come from this discussion was that mandatory dementia training was two hours, but to work in a nail bar required 400 hours of training!

During my visit with the Alzheimer's Association I had the pleasure to meet Arthur, a young psychologist who had relocated from Hong Kong. He explained that in Hong Kong diversity training was predominantly focused on racial diversity, that homosexuality is still very much a taboo subject. He reported that there was virtually no training about LGBTIQ+ issues and an international speaker would be brought in to conduct training where it was present. The ability to live an authentic life was greatly reduced which resulted in increased mental health problems. In this way we can see how societal barriers can impact on the individual.

This is an important consideration especially as the care home sector workforce is so culturally diverse.

This nuanced appreciation of intersectionality both for residents and staff was made more explicit in my conversations with those I met at the Fenway Institute in Boston. It is about having an appreciation for everyone's perspective and not owning or assuming anything which you cannot make claim to. I heard an account of how a dinner club was set up for older members of the LGBTIQ+ community. It was very successful and a plan was made to engage with the BME LGBTIQ+ community. The event was well advertised, refreshments were laid on, etc. but nobody attended. When questions were asked as to why people did not attend, it was felt by the BME LGBTIQ+ community to not be an event for them as it was run by white people. In response to this, the team reached out to the BME community and began a more inclusive process of engagement. I attended the now thriving LGBTI People of Colour dinner on what turned out to be the best Valentine's Day celebration I have ever had. I understood that this was not work which could be done without full engagement with the communities you seek to support and that I needed to be mindful of the intersectionalities and social capital at play if I was going to be able to implement community projects at home.

Figure 8 Memento of Valentine dinner at the Whittier Health people of colour community group

In the stories that I heard from the community I began to appreciate the nuanced nature of this work. For example, I understood that homosexuality had historically been categorised as a mental health issue in the UK, the USA and Australia, these historical parallels were a factor in deciding which countries to visit. I also understood that the LGBTIQ+ community experienced greater mental health problems. As a psychologist, my response would be more counselling services to support this community, not appreciating that for the older LGBTIQ+ community this might be a trigger for conversion therapy. Having this nuanced understanding is important if we are to deliver truly person-centred aged care.

I heard of examples of really good work being done in organisations which historically had not been seen to be particularly LGBTIQ+ friendly. One such faith-based organisation in Boston worked hard training staff to embrace and celebrate the LGBTIQ+ community. This work came about because of a member of the nursing staff who met a young intersex sex worker who was repeatedly abused on the street. She was very moved by this case and nursed the young person until she died. It was these examples of personal stories which often helped to spark organisational change.

I visited the Lifeview care home in the fashionable district of Chelsea whilst in Australia. They were a Rainbow Tick accredited organisation and I wanted to see what this looked like. The reception was a warm welcoming place and evidence of a Rainbow welcome was everywhere. I loved the ethos of Lifeview. It holds with a Home 2 Home care model and had recently transformed its ethos and culture within the organisation, one part of which was the Rainbow Tick accreditation. Wards and wings were now called neighbourhoods, staff were now housemates. There were so many examples of good care at Lifeview but one which stood out in particular and is most relevant to my Fellowship work is that of the Marigold Circle. The Marigold Circle was an initiative put in place as part of the Rainbow Tick accreditation. All residents are invited to this social circle which is hosted on a fortnightly basis. The purpose of the circle is to drink tea, eat cake and discuss LGBTIQ+ relevant issues. A special Marigold Circle was put on to coincide with my visit and I was the guest of honour. The discussion for that day was the plebiscite and there was a fascinating, lively and funny conversation amongst the residents. Some attendees identified as part of the Rainbow community, some had LGBTI+ children and grandchildren and appreciated the social space to talk about them. It was a safe space where they could discuss any worries or concerns they had. It was an honour to attend and hear their opinions and stories. One particular attendee came from another local care home, where he wasn't as open about his sexuality, to join in with the group. His sense of loss and love for his life partner was obvious. His narrative is so important and he was supported to express it without fear.

> "We were together 49 years. I can't believe we were but I worked it out three times. Seems incredible. He thought I was the best thing since sliced bread! He never told me that but he told everyone else and they would tell me. 49 years with one man, we were fairly solid on romance. Still can't believe it was all that time. I've had a very happy life, very happy life." *(Interview with resident, Melbourne, 2017)*

My final visit was a lovely way to end my awfully big adventure. During my doctoral work, I was often politely asked what my research was about. When I explained it was focused on sexuality, intimacy and dementia the conversation often turned to another subject. I felt this was important work, but there was very little being done around this topic at the time. I had read, in those early PhD days, of a care home called the Riverdale Hebrew Home for the Aged, a piece had been written about them in the New York Times explaining how sexual expression was encouraged and welcomed at Riverdale. This one article kept me going in my research on more than one occasion! I was therefore delighted that my invitation to visit was accepted.

I met with lovely staff and wonderful residents and heard of their initiative to introduce date nights to the care home. It was felt by Riverdale that dating was an important part of life regardless of age and that their resident population were largely single. Date nights had proved incredibly popular and I heard from residents and staff that the pre-date excitement that we have all felt at some time did not diminish as you aged. Staff reported how the residents would spend hours getting ready, put on their best bib and tucker, how the dining room was set for tables of two with champagne and canapes followed by a few slow dances. No long-term relationships had yet resulted from a date night, but it was certainly valued by residents and staff alike. I could see the pleasure in taking part in such an initiative as evidence that intimacy and sexuality remain important even into old age.

"It doesn't matter whether you are 17 or 75 the excitement of going on a date is the same. The women would get all dolled up and the men would shave and the excitement was still there, the excitement of meeting someone new was great" *(Interview with care manager of large residential nursing home)*

3. Conclusion

In conclusion, I am deeply grateful to everyone who spent time sharing their stories and their work with me. I have a broadened understanding and appreciation of the issues around aging in the LGBTIQ+ community but I have so much more to learn. Wherever I went I was welcomed with warmth, love and acceptance and will endeavour to promote these values through my work in the future.

From my discussions and observations three important factors emerged in terms of creating positive, inclusive aged care services. Firstly, that having a central Government drive to support LGBTIQ+ issues in ageing helps in terms of creating funding streams and sending a stronger message that this understanding is mandatory, complex, nuanced and important not cursory. Secondly, the organisations who have a strong, embedded LGBTIQ+ friendly ethos such as Uniting, Lifeview, ETHOS and ECH, have created this culture through determined leadership which is informed by the community themselves and in collaboration with academe, policy makers and with quality assurance. Thirdly, the LGBTIQ+ community themselves. I naively thought that I understood some of the issues as an ally, but I underestimated the strength of this community and its deep compassion. The community shared stories of the HIV/AIDS crisis and I slowly realised that the lessons that can be learned around intimacy as a framework of care were already evident within the LGBTIQ+ community. That the community has the answers - we just need to be more open to listening.

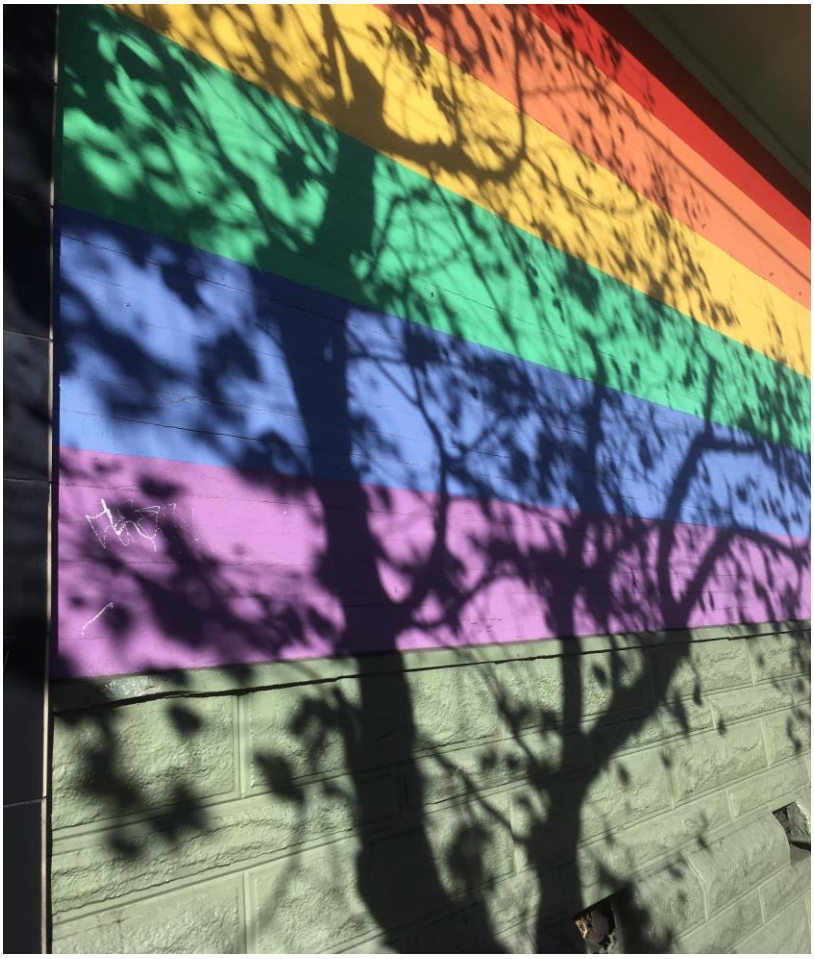

Figure 9 Rainbow art, Castro District, San Francisco

4. Recommendations

Greater Government commitment to address the needs of the older LGBTIQ+ community:

The UK Government has recently released its LGBT Action Plan which seeks to improve the lives LGBT people. This is a welcome initiative but the focus is on younger LGBT community. The Government Equalities Office has pledged to improve understanding of specific groups including older LGBITQ+ people. It is recommended that the needs of older people are included in all aspects of the work being conducted under the Action Plan.

Mandatory cultural humility training for health and social care staff:

There have recently been greater calls for LGBTIQ+ specific training across health and social care sectors. This is strongly recommended. Training was crucial to ensure organisational cultural change but there was a sense that this training needed to be mandatory. When viewed from a rights-based perspective is it essential that organisations address the needs of older LGBTIQ+ people in care. Appreciating that health and social care services already have a lot of mandatory training requirements, it is recommended that a cultural humility approach be taken. Cultural humility is an ongoing process to understand other cultures and to be sensitive and considerate to cultural difference.

Gather reliable data:

The statistical evidence of older adults who identify as LGBTIQ+ in the UK is limited and mostly based on assumptions made by extrapolating the general population figures. Accurate quantitative data needs to be gathered by aged care service providers so we can offer evidence for the need for inclusive aged care and argue for better inclusive service provision.

Hear all the voices and appreciate all the narratives:

The LBGTIQ+ community are a rich and diverse community who have come together to form a powerful political force for change. But within this community there are many voices and narratives which have a lot to offer to the discussions around aged care. It is important that we do not treat the LGBTIQ+ community as on homogenous group, but that we understand the diversity within diversity. The narratives and accounts I heard on my travels were mostly from gay men, lesbian women and the trans community, the intersex community were significantly under represented but may be equally concerned about aging and aged care. We need to find ways in which to encourage engaged with all sectors of this community.

Organisational review:

One way to embed inclusion into organisations is to review the way that organisation presents itself to the world. Organisations can scrutinise every aspect of their working structure to ensure inclusive language use and thus commit to inclusive practice. By reviewing their policies, guidance, websites, job adverts, mandatory and non-mandatory

training, inductions, email signatures, advertising campaigns, all aspects of their organisational literature to ensure non-binary use of language, to promote an inclusive ethos which runs through every aspect of their working practice.

Discussion forums:

A theme which has run through much of my work including my Churchill Fellowship is that of creating safe spaces for learning. I appreciate that talking about sexuality and intimacy can be challenging, especially when we consider aging. The topic is often seen as taboo. One of the ways we can reduce the sense of shame and stigma is to talk openly. We need to find ways in which the LGBTIQ+ community and the aged care sector can talk about their worries and concerns openly and without judgement. This is complex, nuanced work but I strongly believe that people create community, by bringing communities together we can move forward in social change.

Meeting healthcare needs of the LGBTIQ+ community:

Having procedures in place to ensure that the health disparities of the LBGTIQ+ community are understood and recognised by health and social care professionals and supported appropriately, particularly with regard to mental health, PAP screening and prostate checks. Encouraging the LGBTIQ+ community to consider lasting powers of attorney, advanced directives and end of life care to ensure that consideration of their care needs is documented and can be adhered to.

Organisational accountability:

Inclusive aged care is not just for the benefit of LGBTIQ+ residents but also for LGBTIQ+ staff. Inclusivity is about making everyone feel welcome, valued, safe and celebrated. Consideration beyond the residents shows that the organisation is credible in their commitment to inclusive embodiment.

Recognise intersectionality:

A recognition of intersectionality is vital in inclusive aged care practice. Hearing the many narratives and experiences within the community promote understanding and improve services. We must recognise our privileged positions and use them to be part of the solution to enable others to lead and create community services.

5. Next Steps

- Engage with LGBTIQ+ community locally and see how I can inform and develop older people's work.
- Ensure that the older LGBTIQ+ community are included in my future research and community-based projects.
- Read more - I have barely scratched the surface of my understanding, I have so much more to learn from the community.
- Working with local people in my community, create a living archive of their understanding of intimacy in aged care, which unpacks the many voices within the rainbow community.
- Find out more about the national political agenda around ageing and lobby MPs to consider the needs of the LGBTIQ+ community within that.
- Develop an information pack which details the diverse health risks for the LGBTIQ+ community with practical advice on how to meet these needs sensitively.

Appendices

Thank you to the following people and organisations for the warm welcome and time.

Aged Care Complaints Commission - https://www.agedcarecomplaints.gov.au/internet/accc/publishing.nsf/content/home

AlmaVia - https://eldercarealliance.org/residence-options/almavia-of-san-francisco/

Alzheimer's Association - https://www.alz.org/norcal

Carrie Hayter - https://www.carriehayter.com/

Catherine Barrett - https://www.celebrateageing.com/

Copley Square community lunch

Dementia Collaborative Research Centre - http://www.dementiaresearch.org.au/

ECH - https://www.ech.asn.au/

Fenway Institute - https://fenwayhealth.org/the-fenway-institute/

GLHV - https://www.glhv.org.au/

Hebrew Senior Housing - https://www.hebrewseniorlife.org/

Hepburn Health - https://www.hhs.vic.gov.au/

Institute of Health and Aging, University of California - https://nursing.ucsf.edu/academics/departments/institute-health-aging

It's About Time Conference, Melbourne

La Trobe University - https://www.latrobe.edu.au/

Lifeview - https://www.lifeview.com.au/

Matrix Guild - http://www.matrixguildvic.org.au/

National Ageing Research Institute - https://www.nari.net.au/

National LGBTI Health - https://lgbtihealth.org.au/

OpenHouse - https://www.openhouse-sf.org/

RiverSpring Hebrew Home for the Aged - https://www.riverspringhealth.org/hebrew-home/

SAGE - https://www.sageusa.org/

SHINE - https://www.shinesa.org.au/

TransGender Victoria - https://transgendervictoria.com/

Val's Café

Whittier Street Health Centre - LGBT community meal